DESIGN AND EXECUTION OF A STUDY OF READING WITH PRINT LIMITATIONS

Volume 5

From the series "A Survey to Determine the Extent of the Eligible User Population Not Currently Being Served or Not Aware of the Programs of the Library of Congress, National Library Service for the Blind and Physically Handicapped," Volumes 1-5.

Prepared for the National Library Service.

Marvin Berkowitz, Lorraine G. Hiatt, Pamela deToledo, John Shapiro, Margery Lurie

AMERICAN FOUNDATION FOR THE BLIND
NEW YORK 1979

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Research Volumes in This Series:

Volume 1 - Executive Summary—Reading with Print Limitations
Volume 2 - Characteristics, Activities and Needs of People with Limitations in Reading Print
Volume 3 - The Role of Health Care Institutions in Satisfying the Reading Needs of Residents with Print Limitations
Volume 4 - Current Issues in Library Services for People with Limitations in Reading Print
Volume 5 - Design and Execution of a Study of Reading with Print Limitations

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ACKNOWLEDGMENTS

This research series is the result of the cooperation of many people. We are chiefly indebted to the 3,000 individuals and their families in households and institutions across the country who most generously shared information about their lives with us. We are also indebted to staff in nearly 2,000 health care institutions who patiently responded to our questions and warmly facilitated our information gathering, and to the some 50 regional and subregional librarians who provided us with their views on the current issues and functioning of the network of libraries for the blind and physically handicapped. We are also deeply appreciative of the aid provided to us by the staff of the National Library Service for the Blind and Physically Handicapped (NLS), whose useful comments and background materials helped make this project possible.

The study was conceived in response to the need voiced by concerned individuals at many levels for documented data on the prevalence and characteristics of persons eligible for the alternative reading services provided by the NLS. The NLS, which is administered by the Library of Congress, enthusiastically sought monies to research this issue. We wish to acknowledge the continual support throughout our contract of Mr. Frank Kurt Cylke, Director of the NLS, and especially Mr. Richard Evensen, our project liaison officer at the NLS. Their careful review of the entire study process and the various drafts of this manuscript has resulted in what we hope will be a more useful report.

Many staff at the American Foundation for the Blind (AFB) contributed to the project as well. Mr. Loyal Eugene Apple, Executive Director at AFB, provided both encouragement and authorization for the expenditure of Foundation funds to approximately the same extent as the federal contract to complete the work. This support was motivated by the Foundation's view that the study results have broad rehabilitation applicability and provide solid data, heretofore not available. We wish to acknowledge the participation of Corinne Kirchner who made many suggestions as to the study design and the data analysis and reviewed the entire manuscript. Melissa Hager, Carmen Iandiorio, Paul Plummer, Karen Sussman, Alice Ryan, Kathleen Anzalone, Bernice Bloom, Richard Peterson, James Smith and Carol Suhr were other staff members who devoted energies to the project, for which we are thankful.

Unfortunately, we cannot thank each of the many outside contributers by name. We are especially grateful to Dr. Eric Josephson, of Columbia University, for his collaboration in the early stages of our research. His seminal research on the blind was integral to our study design. We are also indebted to Peter Abrams and Richard Faust, of the Calculogic Corporation, who provided data processing support, and to Trendex, Inc., who took responsibility for the telephone field work, which involved identifying and interviewing persons with print limitations.

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OVERALL METHODOLOGY

This study is the composite of four interrelated empirical sub-studies directed at the following research objectives:

1. Estimation of the prevalence and total number of persons in the household population who have physical impairments that limit their ability to read or use regular print.

   This sub-study is referred to as the Screening Study.

2.a) Development of a profile of demographic, social, and reading preferences of persons living at home who have limitations in reading or using regular print materials;

   b) Investigation of the determinants of use/non-use of reading media other than regular print among persons who live at home.

   This sub-study is described as the Call-Back Study.

3.a) Estimation of the prevalence of persons with limitations in using regular print who live in residential and health care institutions, including hospitals, nursing homes, and schools for the blind and/or physically handicapped.

   b) Analysis of the determinants of use/non-use of reading media other than regular print within these settings.

   This study is referred to as the Institutional Study.

4. Analysis of the organization and service delivery mechanisms of the network of state and local libraries for the blind and physically handicapped that provide special reading materials to

persons with reading disabilities.

This is referred to as the Regional Library Study.

In each of these sub-studies, as the work evolved, the directions that the research took hinged on many decisions. To help the reader judge our interpretation of the data, or to make further interpretations, a detailed discussion of the research methodology is provided. Further treatment of methodological issues may be found in the sections describing the component studies and in appendices.

The research was performed under contract for the National Library Service for the Blind and Physically Handicapped, operated by the Library of Congress. There has been no prior empirical research specifically aimed at estimating the size and characteristics of the population eligible to use the NLS/BPH service, or exploring reasons for non-use of service among the eligible population.

The basic study goals were specified in the Request for Proposal by the National Library Service/BPH in April 1976. Response to these goals in light of the existing disability literature suggested a conceptual framework which distinguished between persons living at home and persons living in health care institutions. The number of people living in households who are potential users of reading media other than regular print is considerably greater than that of persons living in health institutions. The process of identifying the target population living at home is also more complex than identification of institutions.* Therefore, the balance of energy and time were devoted to the

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*Primary data collected by the National Center for Health Statistics

household component of the research. A third component related to the regional library services and the impact of the service delivery system on utilization of the NLS/BPH programs was added as the study evolved.

Cost and time constraints were critical factors in determining specifics of the research design. The only constraint specified in the Request for Proposal was that the work should be completed in approximately fifteen months. A modest budget allocation was anticipated. On the basis of these considerations, several survey approaches which might have been preferable had to be excluded in favor of more efficient methods.

PROBLEMS OF DEFINITION

Virtually every recent study of disability (Berkowitz, et al.(1976); Gallin and Given (1976); Nagi (1977); Haber (1967); Dudek, et al. (1976)) has pointed out obstacles to performing such research that result from ambiguous definitions of functional disabilities, and the absence of

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(NCHS, 1978) and data analyzed by Westat, Inc. (1976), indicated that the prevalence of persons with reading disabilities institutionalized in the country's 30,000 nursing homes, hospitals, and other health care institutions is roughly 10% of the total household population. But in terms of demand for the NLS/BPH service, the institutional population was a most important one to the survey. The reading needs of these persons may have a higher potential for being served because of evidence that institutional staff know of and organize use of the NLS/BPH program. Data from the NLS/BPH suggested that persons in over half of the nation's institutions were utilizing alternates to regular print in 1977.

standard ways of measuring them. One of the primary reasons cited by the National Eye Institute for discontinuing in 1971 its efforts to prepare regular estimates of the prevalence of legal blindness was that uniform data of comparable coverage were not being reported, even by ophthalmologists and optometrists.

Distinction Between Disorder, Impairment, Disability and Handicap

Nagi (1977), Haber (1969), and Colenbrander (1976, 1977) offer analyses to eliminate the frequent conceptual confusion among the terms "handicap," "disability," "impairment," and "disorder." "Disorder" is a term relating to the underlying pathology of a specific part of the body. Two examples of disorders that may or may not result in reading difficulties are: 1) the inability of the pancreas to metabolize carbohydrates, which interferes with the breakdown of fats and proteins (diabetes mellitus), and 2) a disorder of the central nervous system characterized by sudden seizures due to abnormal electrical discharges of brain cells (epilepsy). Cataracts, or opacities of the crystalline lens of the eye, would be an example of a disorder affecting reading ability. "Impairment" is a concept related to the function of an organ or component of the body as a whole. It is a term identifying the presence of physiological, anatomical, intellectual, or emotional losses. Further specification provides information on the extent or severity of an impairment. Three visual impairments are 1) loss of acuity, 2) decrease of the field of vision, and 3) loss of contrast sensitivity. They relate to function of the eye as a whole, as compared to a disorder of the retina, which might cause the impairment.

The concept of "disability" relates to the physical and mental capacities of an individual to perform specific tasks or functions, e.g., reading, bathing, eating, bending, sitting, standing. Sometimes the concept of "disability" is extended to relate an individual's capacity to perform roles (i.e., sets of tasks) in different social settings, such as working at a paid job or attending school. Sometimes "handicap" is used interchangeably with "disability," although it is preferable to reserve the term "handicap" for the interaction of the individual's functional capabilities with the requirements of the environment. For example, Bowe (1978) argues that "handicaps" depend not only on the individual's skills and motivations, but also on the obstacles created by the society, i.e., accessibility which is affected by physical barriers and/or attitudes of others.

Although the loss of sight is an impairment for every blind person, and results in some degree of disability in performing various functions, it may or may not be a handicap, depending on the individual and the situation. For example, persons so disabled as to need the attendance of a companion to travel in unfamiliar surroundings may be granted reduced fares by interstate carriers as a result of amendments to the Interstate Commerce Act, thereby reducing their travel handicap but not the disability.

For the purposes of our study, the definition of disabilities limiting use of print materials is taken from the conditions of eligibility for the NLS/BPH program as prescribed by Congress in Public Law 89-522 and are given below.*

(b) Eligibility Criteria. (1) The following persons are eligible for such service:

(i) Blind persons whose visual acuity, as determined by competent authority, is 20/200 or less in the better eye with correcting glasses, or whose widest diameter if visual field subtends an angular distance no greater than 20 degrees.

(ii) Persons whose visual disability, with correction and regardless of optical measurement, is certified by competent authority as preventing the reading of standard printed material.

(iii) Persons certified by competent authority as unable to read or unable to use standard printed material as a result of physical limitations.

(iv) Persons certified by competent authority as having a reading disability resulting from organic dysfunction and of sufficient severity to prevent their reading printed material in a normal manner.

(2) In connection with eligibility for loan services "competent authority" is defined as follows:

(i) In cases of blindness, visual disability, or physical limitations "competent authority" is defined to include doctors of medicine, ophthalmologists, optometrists, registered nurses, therapists, professional staff of hospitals, institutions, and public or welfare agencies (e.g., social workers, case workers, counselors, home teachers, and superintendents). In the absence of any of these, certification may be made by professional librarians or by any person whose competence under specific circumstances is acceptable to the Library of Congress.

(ii) In the case of reading disability from organic dysfunction, competent authority is defined as doctors of medicine who may consult with colleagues in associated disciplines.

(c) Loans through regional libraries. Sound reproducers are lent to individuals and appropriate centers through agencies, libraries, and other organizations designated by the Librarian of Congress to service specific geographic areas, to certify

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*Sec. 701.10 "Loans of library materials for blind and other physically handicapped persons." In Federal Register 39, No. 111 (1974): 20203-20204.

eligibility of prospective readers, and to arrange for maintenance and repair of reproducers. Libraries designated by the Librarian of Congress serve as local or regional centers for the direct loan of such books, reproducers, or other specialized material to eligible readers in specific geographic areas. They share in the certification of prospective readers, and utilize all available channels of communication to acquaint the public within their jurisdiction with all aspects of the program.

(d) National collections. The Librarian of Congress through the Division for the Blind and Physically Handicapped, defines regions and determines the need for new regional libraries and deposit collections in cooperation with other libraries or agencies whose activities are primarily concerned with the blind or physically handicapped. The National Collections located in the Division for the Blind and Physically Handicapped serve as one such regional center, and provide services to other libraries, and to blind and physically handicapped readers anywhere in the nation requiring specialized materials. It serves as the center from which books, recordings, sound reproducers, and other specialized materials are lent to eligible blind and physically handicapped readers who may be temporarily domiciled outside the jurisdictions enumerated by the act.

(e) Institutions. The reading materials and sound reproducers for the use of the blind and physically handicapped may be loaned to individuals who qualify, to schools for the blind or otherwise handicapped, and to institutions for the use of such persons only. The reading materials and sound reproducers may also be used in public or private schools; however, the individual students who qualify must be the direct and only recipients of the materials and equipment.

(f) Musical scores. The Division also maintains a library of musical scores, instructional texts, and other specialized materials for the use of the blind and other physically handicapped residents of the United States and its possessions in furthering their educational, vocational, and cultural opportunities in the field of music. Such scores, texts, and materials are made available on a loan basis under regulations developed by the Librarian of Congress in consultation with persons, organizations, and agencies engaged in work for the blind and for other physically handicapped persons.

(g) Veterans. In the lending of such books, recordings, reproducers, musical scores, instructional texts, and other specialized materials, preference shall be at all times given to the needs of the blind and other physically handicapped persons who have been honorably discharged from the Armed Forces of the United States.

Varieties of Altered Reading Behavior

The difference between NLS/BPH's definitions of disabilities determining eligibility of persons to be included in this study and the classification of reading disabilities proposed by reading specialists was a fundamental issue for our research. A review of the reading disorder and improvement literature showed that a wide variety of methods are used in classifying reading disabilities. Some describe functional behavior, others causative factors (etiology), communicative-language factors, or diseases. Both reading and oral reading were initially examined for their relation to limitations in using print materials.

The functional classification system focuses on discrete descriptions of altered behavior that can often be observed by librarians and classroom teachers. Among the functional systems used by researchers, a combination of those proposed by Blom and Jones (1972), and Monroe (1932) was deemed most useful.

Altered behavior is described within eleven functional groups:

A. Difficulties related to the visual aspects of reading:

1. seeing - visual acuity, visual field, contrast perception
2. visual memory
3. visual sequencing
4. visual recall
5. visual discrimination
6. visual-motor coordination
7. figure-ground discrimination
8. form constancy
9. other perceptual disorders.

B. Difficulties related to spacial orientation:

1. position in space
2. spacial relationships of objects
3. directional orientation
4. orientation for right-left, up-down, in front of-behind, and over-under.

C. Difficulties related to kinesthetic aspects of reading:

1. balance
2. posture
3. locomotion, difficulties in holding or turning
4. fine and gross motor coordination
5. clumsiness
6. feeling, sense of muscular motion, position
7. impulsive reaction
8. hyperactivity
9. distractability
10. confused laterality
11. confused body awareness
12. ambidexterity
13. handwriting, the reproduction of forms
14. touch sensitivity
15. tactile discrimination
16. weakness.

D. Difficulties related to the auditory aspects of reading:

1. auditory acuity
2. auditory memory
3. auditory sequencing
4. auditory recall
5. auditory discrimination
6. preservation of beginning sounds
7. listening
8. auditory-visual transposition.

E. Difficulties related to the motor aspects of reading.

1. lack of precision in motor control of eyes
2. lack of motor control of speech
3. lack of precision in directional motor responses.

F. Difficulties related to the conceptual aspects of reading:

1. lack of vocabulary
2. lack of facility in the organization of language
3. poor memory, particularly for symbol representation
4. poor association of meaning with symbols
5. unique patterns of conceptualization
6. intelligence quota (I.Q.).

G. Difficulties in the development of speech and language:

1. irregular speech development
2. slow speech development
3. speech impediments
4. verbal fluency
5. blending and/or synthesizing sound
6. inner language transformations.

H. Difficulties related to temporal competency:

1. rhythm sequence
2. synchrony
3. orientation to clock or calendar time.

I. Difficulties related to the methodological aspects of reading:

1. overstress of speed of reading
2. overstress of some methods of word-recognition.

J. Difficulties related to emotional aspects of reading:

1. short or varying attention span
2. resistance to reading
3. fear, timidity
4. withdrawal
5. low frustration tolerance, anxiety
6. asocial (poor interpersonal relationships)
7. emotional instability
8. poor motivation
9. easily discourgaged, failure syndrome
10. poor self-concept, easily embarassed
11. inappropriate behavior
12. depressed
13. low energy level
14. other personality elements
15. maturity in relation to school adjustment.

K. Difficulties related to environmental aspects of reading:

1. foreign language
2. illiterate parents
3. cultural deprivation, social milieu
4. truancy and poor school attendance, neglect of schooling
5. frequent moves from school to school
6. poor instruction
7. number of siblings, ordinal position of child, playmates.

The application of these eleven functional groups of altered reading behavior to the conditions limiting use of print material for which the NLS/BPH provides alternative reading services presented some conceptual and practical difficulties. In part, these problems result from the overlapping and interacting causes of undistinguished relative significance for most reading disabilities. Often associated concomitant behavior in an individual may or may not be related to the limitations in reading. In part, these problems relate to the severity of a limitation or the remaining level of competence in reading.

The problem of applying the NLS/BPH criteria to the range of observed altered reading behavior also relates to our decision to rely on self-reporting, or the reporting by a family member or health care professional, rather than clinical certification as the basis for inclusion in the study. This decision reflected our primary interest in the nature of the altered reading behavior produced by an impairment, rather than in descriptions of the anatomical symptoms of the disorder, its medical diagnosis, or its cause. Yet the NLS/BPH eligibility criteria intermingle performance and impairment definitions, complicating interpretation or adherence to a single conceptual schema. For example, the operational measurement of visual acuity and vision fields is one criterion of eligibility, while functional performance in terms of ability to read is another means of certification.

The NLS/BPH criteria seem clearly to incorporate a number of groups of reading disabilities proposed by reading disorder specialists, but exclude several others. The factors of audition and speech

and their significance for learning to read, were particularly in question. As a practical matter, deaf persons and persons with speech impediments who reported having reading difficulties but not specifically in the use of regular print materials (in silent reading), were excluded from the survey.

The large set of learning disabilities associated with conceptual aspects of reading, temporal competency, and methodological aspects of reading are loosely covered by NLS/BPH eligibility criteria under the title of "organic dysfunctions." But respondents typically did not know or provide data on whether problems in cognition and intellectual functioning were of a physiological or an emotional origin, or were affected by contributing factors such as motivation. Some emotional disorders commonly cause a general loss of capabilities in associative function, ability to organize thought, and to control movements that are essential for reading. Furthermore, emotional disorders like schizophrenia or autism might result from metabolic or chemical abnormalities that are physiological in origin. In the majority of cases of persons reporting emotional disorders, significant vision or physical impairments were also mentioned. Thus, the question of ascertaining eligibility for this group was somewhat less serious.

The concept of adaptive "normal" behavior or "mentally ill" behavior and its manifestations was especially problematic; this category also seems to be a source of confusion for administrators handling applications for the National Library Service/BPH.* It poses particular

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*See report on the regional library network prepared as a sub-study of this report.

difficulties in making eligibility decisions for adults who have functional deficits of uncertain or multiple origin: many labels can be used for the same functional disability. If an applicant chooses the right label (a physical disability), he/she may be deemed eligible. But if he/she selects a less clear label (such as mental disorder resulting from physical impairment), eligibility may be denied. In practice, the adjudication of eligibility for persons claiming "organic dysfunction" is a difficult determination, and has posed some administrative problems for libraries and referral agencies.

The treatment of persons who reported that they had never learned to read or could not read English also presented problems. A number of factors may account for illiteracy or functional illiteracy in English. Four important factors are: a) subaverage intellectual functioning--existing concurrently with deficits in adaptive behavior (mental retardation); b) cognitive deficits associated with emotional disorders; c) non-attendance at school due to physical problems (common among children with cerebral palsy, etc.); d) foreign upbringing. Persons who were not able to speak English were also excluded, because funds did not permit foreign language speaking interviewers. This is an obvious study limitation, since 11 million Americans use a language other than English as their primary language of discourse.

The study team was concerned about persons who might not be able to learn to read because of perceptual or spatial disorders, but who might be able to learn to read by listening to recorded versions of printed material. Where appropriate, these persons were included in the survey,

since exclusion of this type of learning disabled person, the "non-print" reader, would be contrary to eligibility criteria recognizing limitations in vision, dexterity, weakness, etc.

Lower Age Limit on Persons Included in Study

It was necessary to establish a minimum age for persons included in the study. Six years of age was selected, because it is the age that children in the United States normally begin to learn to read in the school systems.

READING AS A CULTURAL ACTIVITY

To summarize the definitional issues, this study focussed on identifying and describing persons with disabilities in reading regular print, in order to estimate the potential demand for an alternative reading service. To fulfill this objective, the study adopted a marketing orientation rather than a health research orientation. The resulting data may be compared only with great caution to national estimates of persons with impairments in seeing, motor control, or cognitive-intellectual functioning that may result in reading disabilities. Persons who report that such impairments limit their ability to read print implicitly indicate an interest or previous experience in reading. As noted above, reading is a socio-cultural activity affected by factors other than physical attributes.* Therefore, persons who do not report a disability in reading

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*In some ways, such comparisons are rather like exploring why some persons with severe physical impairments are unemployed. They may not work because

may not read, either because they cannot, or because they place a low priority upon the activity.*

Equating the prevalence of persons who report physical disabilities in reading regular print with the prevalence of one or more physical impairments (one person may have several) that may affect reading behavior: a)confuses the number of impairments with the number of people; b) underestimates the potential of individuals to adapt to these impairments; c) overestimates the interest in reading. This point is critical when statistics on needs are utilized or interpreted for funding agencies.**

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they are too ill, too young or too old, have no skills, feel there are no jobs for them, are independently wealthy, are too busy doing other things, feel threatened by dealing with the work environment, or a combination of many of these factors. Clearly, it is not simply the case that the presence of physical impairment determines their lack of employment. See Hyman (1975); Aiken (1976); also Robinson (1969).

*For a discussion see sources cited in Chapter 1 and Ruddell (1970).

**The designation of a "disability" is also dependent on an individual's attitude and ability to adapt to a severe impairment. For example, some persons may consider blindness as merely an inconvenience for reading if they have developed satisfactory coping techniques.

DEPENDENCE UPON FAMILY MEMBERS OR HEALTH CARE PROFESSIONALS AS RESPONDENTS

A significant factor in executing this study was the dependence upon proxy respondents for information and opinions. In the household study, family members of persons with disabilities in reading print frequently participated in the interviews, especially where the disabled person was a child under 16 years old. This problem was "built in" by cost constraints that resulted in the decision to limit face-to-face interviews. Interview techniques other than personal visits introduce bias because telephone and mail survey approaches involve physical capacities (holding or writing) which were known to be restricted in a portion of the target population. For example, in about 20% of the study households, it was reported that the desired adult respondents were unable to talk on a telephone or to come to the telephone to be interviewed due to physical disabilities.

It is difficult to assess the relative accuracy and completeness of information obtained through proxy respondents. Family socio-economic condition, life style and attitudes affect all aspects of a family member's life, including reading interests. Household members are often involved in obtaining materials or reading to or with the disabled person--and serve as intermediaries to the outside world.

In the institutional study, due to the infeasibility of interviewing large numbers of patients or examining their files, the basic unit of analysis was taken as the institution rather than the individual. This was thought to be appropriate because staff, policies, and even institutional facilities often mediate between residents and their use of the NLS/BPH program even more so than the family in households. The decision to treat the institution as a basis for sampling coincides with the distribution of NLS/BPH reading materials and equipment to institutions for collective use by some of its eligible persons. (Although individuals may subscribe to the NLS/BPH program and receive their own reading materials, a great many institutions do not appear to distinguish between equipment and materials for individual use compared to collective use.)

As proxy respondents, household members differ substantially from institutions. Household members incur little risk of social disapproval by stating that they are not personally interested in reading, since such a response would not reflect poorly on a whole "system" (i.e., the household). The institutional staff, however, to a far greater extent may introduce personal feelings about the importance of reading in the context of the institution's goals, and thus might make judgments that cast the institution in a favorable light.*

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*Staff of institutions may have felt that participation in NLS/BPH programs is a "good concept and that it would be negative to the organizational image if they did not offer such a service. This might tend to inflate the numbers of institutions reported to possess recording equipment

A staff member also may not be fully knowledgeable about all residents; unlike a household member, a staff member may see individuals only for a brief interval (generally not exceeding eight hour shifts). Times of the day when reading might occur could be those hours when staffing levels are lowest; staff judgments therefore might underestimate or overestimate reading behavior based on the types and numbers of residents they personally come in contact with in their work.

These factors, then, result in a situation where errors in estimation in the institution become more complex. When errors are made, they tend to statistically influence a much wider segment of the population.* For example, a number of statistical projections made in this study are derived from secondary reports (i.e., staff estimates) rather than from primary contacts (direct survey of each resident), and thus are subject to greater errors. Statistical summaries developed from individual data closely approximate the prevalence of reading disabilities, reading interests, and habits--since the people giving reports typically live together in small units. A parallel situation does not exist in the

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to read by listening--but, particularly in institutions, possession perse is a questionable basis for estimating interest of residents, usership and frequency of use. See Hughes and Peters (1978); Kosberg and Gorman (1975).

*There may be a tendency to underestimate reading disabilities indicated by the finding that few institutions regularly test vision. This might influence potentially eligible users of the NLS/BPH program, especially among the longer stay facilities, where people who might "age into eligibility" are not picked up through screening. This is further complicated with eligibility. The need is expounded by Shore (1976).

institutional setting, particularly the larger institutions where numbers of staff and job specificity both increase. This difference suggests a source of error in statistical projections in the institutional study not found in the household.

ESTIMATION OF SURVEY PRECISION

All sample surveys are subject to "sampling variability," that is, the extent to which the results may differ from what would be obtained if the whole population from which the sample was drawn had been interviewed. The size of such sampling variability depends largely on the number of interviews and the sample design.

In this study different designs were used for each of the substudy components. For the screenings, three independent replicated samples of the same design were pooled to provide composite estimates of prevalence by age, sex, region, etc. For the call-back study, stratified random samples were drawn from the screenings, and the data were weighted to reflect the sampling proportions and response rates. In the institutional mail study, systematic random samples were drawn from different sample frames and those results pooled. Although the degree of precision of each of these samples differs, for convenience the following tables may be used in estimating the approximate sampling variability of any percentage in this report.* The allowances may be interpreted as indicating the range of variability (plus or minus percentages in the findings) that results of repeated samplings could be expected to fall into due to chance factors, 95 percent of the time--assuming the same period, same sampling procedure, same interviewers, and same questionnaire.

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*For the household study, projections of the national population may be reduced by a factor of about 1100 and the resultant figures used as approximate sample sizes in the tables. For the most part, results in the household study are given for the weighted sample size. The approximate sample sizes for use in estimating sampling variability can be obtained by dividing the weighted sample sizes by 3.58.

Table 1-1 shows how much allowance should be made for the sampling variability of a percentage, depending on the magnitude of the percentage and the size of the base number for calculating the percentage.

Table 1-1 would be used in the following manner: Let us say a reported percentage is 23% for a group which includes 1000 respondents. Then we go to row "Percentages near 20" in the table and go across to the column headed "1000." The number at this point is 3, which means that the 23% obtained in the sample is subject to a range of sampling variability of plus or minus 3 points. Another way of saying it is that very probably (95 chances out of 100) the average percentage obtained in repeated samplings would be somewhere between 20% and 26% with the most likely figure of 23% obtained.

In comparing survey results in two samples such as, for example, whites and non-whites, the question arises as to how large must a difference between them be before one can be reasonably sure that it reflects a real difference. In Table 1-2, the number of points which must be allowed for such comparisons is indicated.

Here is an example of how Table 1-1 would be used: let us say that 62 percent of whites respond a certain way and 55 percent of non-whites respond that way also, for a difference of 7 percentage points between them. Can we say with any assurance that the 7 point difference reflects a real difference between whites and non-whites on the question? That is to say, would an observed difference between two percentages that is equal to or greater than that shown in Table 1-2

Table 1-1

Allowance for Sampling Variability (in Percent) by Size of Sample

Reported Percentage	2000	1500	1000	750	600	400	200	100
Percentages near 5 or 95	1	2	2	2	3	4	4	5
Percentages near 10 or 90	2	2	2	3	3	4	5	7
Percentages near 20 or 80	2	2	3	4	4	5	7	9
Percentages near 30 or 70	3	3	4	4	4	6	8	10
Percentages near 40 or 60	3	3	4	4	5	6	8	11
Percentages near 50	3	3	4	4	5	6	8	11

Table 1-2

Allowance for Sampling Variability (in Percent) of the Differences in Percentages Between Two Different Survey Subgroups, by Size of the Subgroups (at 95 in 100 Confidence Level)

SIZE OF LARGER SAMPLE	25	50	75	100	150	200	250	300	400	500	600	700	800	900	1000	1500	2000
25	28																
50	24	20															
75	23	18	16														
100	22	17	15	14													
150	21	16	14	13	11												
200	21	16	13	12	11	10											
250	21	15	13	12	10	9	9										
300	20	15	13	11	10	9	8	8									
400	20	15	12	11	9	8	8	7	7								
500	20	15	12	11	9	8	8	7	7	6							
600	20	15	12	11	9	8	7	7	6	6	6						
700	20	14	12	10	9	8	7	7	6	6	6	5					
800	20	14	12	10	9	8	7	7	7	6	5	5	5				
900	20	14	12	10	9	8	7	7	6	6	5	5	5	5			
1000	20	14	12	10	9	8	7	7	6	5	5	5	5	5	4		
1500	20	14	12	10	8	7	7	6	6	5	5	5	4	4	4	4	
2000	20	14	12	10	8	7	7	6	5	5	5	4	4	4	4	3	3

SIZE OF SMALLER SAMPLE

occur 95 out of 100 times due to factors other than random error or sampling variability? The numbers responding consist of approximately 500 whites and 100 non-whites.

This table is based on sample sizes ranging from 25 to 2000 observations and can be used for typical sample sizes within this range, regardless of whether the two independent samples have the same number of observations. The calculations of statistically significant differences in the table are most appropriate for comparing percentages within the range of between 25% and 75%. A comparison of the difference between percentages that are both below 25% or both above 75% will be less precise using Table 1-2 and reference to a standard statistical work like Kish (1965) is recommended.

First we look in Table 1-2 along the left hand side for the row near the larger sample size of 500. Now, going across this row we find the column closest to the smaller sample size of 100. We find the number 11 here. This means that the allowance for sampling variability in repeated samplings of the similar populations should be 11 points. Since the observed difference between whites and non-whites is only 7 points, we say that the 7 point difference is inconclusive. If in another case, the responses of whites were 29% and those of non-whites were 44%, a difference of 15% would obtain. In concluding that the percentage of whites is somewhere between 4 (15 minus 11) and 26 points (15 plus 11) lower than the percentage of non-whites, we should be wrong only about 5 percent of the time. Hence, we conclude with confidence that the observed difference is a real one.

METHODOLOGY FOR THE SCREENING STUDY-HOUSEHOLD POPULATION

The Screening Study had three primary purposes:

1) To determine the prevalence of persons with limitations in reading regular print within the U.S. household population.
2) To determine some basic demographic and disability characteristics of this population.
3) To identify a sample to be contacted at a later time for in-depth call-back interviews.

IDENTIFYING AND SAMPLING A RARE POPULATION WHICH MAY NOT WISH TO BE FOUND

Among the preceding research questions, the location of a representative sample of persons in the household population with reading limitations was the most pressing issue because of the relative rarity and wide dispersion of this group. A second obstacle for the research was the attempt to locate persons who may not wish to be identified, because they want to avoid being labelled as "impaired" or "handicapped." Under-reporting, or the identification of "false negatives" (persons who have disabilities and choose not to report them) is perhaps the most serious issue affecting the accuracy of health survey results. Studies by the National Center for Health Statistics (NCHS, 1977, 1969, 1967, 1965) have examined under-reporting of health conditions as an effect of social and personal threat. Some of the interviewing techniques suggested by NCHS to minimize such "censoring" have been applied in this study. Nevertheless, underreporting is still considered significant. In addition, it is possible that many impairments are undetected or mild, and thus are not disabling,

or may be only temporarily disabling. These may be latent (as in the case of age-related vision deterioration). The estimation of such latent cases might be attempted using incidence data based on clinical exams, but this is likely to be extremely unreliable.

A review of the disability literature prior to designing the sample suggested that the prevalence rate for persons with print handicaps is about one percent of the United States population (Goldstein, H. and Josephson, E., 1975; Westat, Inc., 1976). Sampling specialists (Hansen, et al., 1953; Kish, 1965) have devised methods to locate such rare populations accurately for interviewing, but these methods were more expensive and time consuming than viable in this study's research design.

The ability to perform major portions of this research came about largely as a result of the extension of home telephone use in the last ten years, and recent refinements and economics in national telephone sampling techniques.* Since Josephson demonstrated the efficacy of telephone surveying for disability studies in 1967, the approach has been widely adopted.** Josephson was able, by telephone, to obtain screening of severe

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*For a survey of recent telephone interview studies, see Survey Research 5 (1973).

**See, for example, Allen and Benson, (1978).

visual impairments that provided prevalence rates comparable to those determined by the National Center for Health Statistics (NCHS) through its Household Interview Survey (HIS). Josephson also showed that the "hidden blind" in Cleveland--those unknown to the Cleveland Society for the Blind--outnumbered those known to the blindness system.*

Using Josephson's example and other studies that have since demonstrated the comparability of telephone surveys and personal interviews,** the decision was made to screen the national population by telephone.

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*In Josephson's analysis of age, income and household characteristics, he found that the "hidden blind" tended to be older, and to have first experienced blindness in middle or later years. This "hidden blind" population, the group that NLS/BPH is also seeking to find, apparently get little help in spite of their considerable needs. In Josephson's sample, more than half expressed a need for social and medical services. The "hidden blind" also tended to be poorer than those known to agencies, and were more likely to report multiple chronic conditions. All of these findings are substantiated by results from our study.

**Over the years, both the quality of response by telephone, as measured by the willingness to provide personal information, completeness, consistency and accuracy of the information, and the ability to answer complex questions have improved markedly. Telephone interviews are now accepted on par with face-to-face interviews in quality. Measures of field performance, e.g., response rate, length of interview, number of contacts required, preferable times for interviewing, interviewer strategy and effects also show comparability. For complex personal questions, studies indicate that respondents are slightly less likely to say that they "don't know" in telephone interviews as compared to personal meetings. Telephone interviews also eliminate the reluctance to open doors to strangers or to interview people who are sitting comfortably. Research also shows that older people (more prone to disabilities) prefer to be interviewed over the telephone rather than in person. See Rogers (1976).

In 1976, some 95% of the U.S. population had telephone service. The state by state rates vary from nearly 100 percent to a low of 83 percent, with lower utilization of telephones by the poor and in the South.* However, in spite of such variations, this study accepts the premise that the telephone is a crucial link to the outside world for many blind and physically impaired persons and their families--especially the older population that makes up the largest proportion of potential users of the NLS/BPH. With restricted mobility, disabled and older persons come to depend on the telephone to shop, to talk to friends and relatives, and overall, appear to utilize it as a primary mode of communication for personal conversations outside their households. Some 160,000 persons with visual impairments and 186,000 persons with paralysis indicated in 1967 that they were confined to their homes and could not go out.** To these groups the telephone is a necessity for health reasons when nobody else is at home. Since approximately twenty percent of the visually impaired who cannot read newsprint do live alone, a telephone is likely to be essential. These same factors are thought to be at least as significant for other physically handicapped persons.

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*U.S. Department of Commerce, Bureau of the Census. Statistical Abstract of the United States - 1978 p. 590.

**NCHS, Vital and Health Statistics Series 10, No. 61 (1971).

"PIGGYBACK" ON AN ESTABLISHED "OMNIBUS" SURVEY

In order to obtain a national sample sufficiently large to permit estimation of prevalence rates with maximum economy and efficiency, it was decided to "piggyback" a short screening survey upon an established national area probability sample.* Virtually the only organization utilizing a large enough omnibus survey was Trendex, Inc., a market research firm experienced in conducting product and media studies. Trendex conducts national telephone screenings four times a year using listed telephone numbers. At half year intervals, some 70,000 households are sampled. At alternative quarters, a dual wave of 140,000 interviews is conducted. (A description of the Trendex Sample is given in Appendix F). Although very few questions could be added to the Trendex survey, it was possible to screen a very large sample

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*Among the excluded approaches was a relatively standard one for locating and identifying populations, suggested by Hansen, et al. (1953). This technique has been used by Schein and Delk (1974) to estimate the deaf population in the United States. The first step in this approach is to develop a comprehensive list of persons with problems through contacts with agencies of and for the disabilities, articles and announcements in the media, church and social service groups, schools, private physicians and health care institutions, and by asking known disabled persons for the names and addresses of other disabled persons ("snowballing"). Second, all compiled names would be verified to see if they indeed had a disability. That is, it would not be adequate merely to locate people with impairments that might affect reading: a large scale mail or telephone survey would be required to validate the compiled list. For this study, the list-building approach was felt to be too expensive and time consuming. It was not certain whether the cooperation of the helping agencies could be obtained in sharing names of disabled persons, for reasons of confidentiality.

of the national population rapidly and inexpensively.

Random digit dialing (RDD), which would have been preferable to obtain better representation, was not financially feasible. It was hoped that we could validate the disability identification rates by using listed telephone numbers against those obtained from random digit dialings for major cities where unlisted phones are more common. Budget constraints, however, precluded this procedure.

During 1977, three independent sampling waves of 70,000 households each were conducted for AFB by Trendex. Overall, 214,177 households reported information on the reading performance of their approximately 620,000 family members.

The precise wording of the introduction and questions asked were:

> Next, I'd like to ask you some questions that are really quite different from the ones I've asked before. They have to do with certain free public library services. After I read you the questions, please answer "Yes" or "No" if any one of the three questions applies to your household.
>
> A. Are there any members of your household, including yourself, who are unable or find it difficult to read regular print even with eye glasses?
> B. Are there any persons who are unable or find it difficult to hold or turn the pages of a book or magazine?
> C. Are there any persons having reading difficulties because of any other physical problems?

The multiple screenings were designed to supply a representative national sample of persons for "call-back" interviews. In these call-back interviews a detailed instrument lasting approximately sixty minutes explored the social and demographic characteristics

of the disabled person and his/her household, the individual's health and mobility, his/her attitudes, interests, and hobbies. These interviews defined more precisely the individual's limitations in reading and performing activities of daily living.

Since the research objectives called for analysis of several different types of reading disabilities and age groups, it was necessary to use a fairly large sampling frame. The goal was to obtain completed interviews from about 2,000 persons in order to conduct the desired analysis.

Second, it was also important to test the reliability of the survey questions. The consistency of results in each of the waves (see Table 2-1) indicated a very low sampling variability.

PRETESTS

The precise wording of the screening and call-back questions was determined through review and negotiation with the National Library Service/BPH. Each question was critiqued for its relation to the mission of the NLS/BPH in providing reading services and its relevance to the specific purposes of this study.

Several versions of the introduction and screening questions were pretested and respondents' reactions were considered carefully. It was found that the words "federal" and "Library of Congress" were not well received. For example, refusals occurred with greater frequency when the interviewer said that the survey was for the "Library of Congress." Reference in the introduction to improving a "federal program" was eliminated after obtaining

Table 2-1

Total Number of Households with Reading Problems
from January and April 1977 Waves--Broken Down by Problem

Problem	Number of Households from January Wave	Percent	Number of Households from April Wave	Percent	TOTAL	PERCENT
Total number of households called	142,886		71,391		214,277	
Visual	3,345	69	1,576	69	4,921	69
Physical	642	13	262	12	904	13
Learning	510	11	203	9	713	10
Undetermined	68	2	132	6	200	3
Refused	257	5	84	4	341	5
TOTAL =	4,822	100	2,257	100	7,079	100

frequent responses such as "I don't want any of that, goodbye." The initial wording was simplified to increase understanding.

Because the National Library Service/BPH mandate to provide services to persons with cognitive-intellectual disorders is somewhat ambiguous, the wording of the screening questions specifically excluded naming these problems, but allowed for them to be coded in response to the general question, "are there any persons who find it difficult to read because of any other physical problems?" The high percentage of learning disabilities identified is especially significant in light of this approach.

The identification rate (i.e., reports of persons identified as print disabled) in the pretest of about 600 households randomly selected from listed phone numbers in Fairfield and Bridgeport, Connecticut and Queens, New York was about half of one percent. This low identification rate, as well as interviewer suggestions, indicated to us that it was better to have a simple initial screening question and then to probe for additional details only for the identified target persons.

INTERVIEW PROCESS IN SCREENING STUDY

Incorporation of Questions in the Omnibus Survey- The interview schedule, in which the screening questions on reading were included, consisted of twenty questions about the purchase of commercial products, about demographic and social characteristics, and also our screening questions about reading. If an affirmative answer was given to any of the screening questions, the respondent was then

asked additional items on age, sex, nature of reading disability, duration of the disability, ability to use the telephone, the presence in the household of other family members with reading disorders (see Appendix A). Since a lengthy series of questions was not possible, the reading disorders reported were taken as primary problems rather than the respondents' only reading disability.

Time of Interviews- The screening interviews were conducted throughout the week in the evenings, between the hours of 7 and 10 p.m. As noted, the interviews were performed in three waves. The first wave was conducted during the first two weeks of January 1977. The second wave was conducted during the last week of January and the first week of February 1977. The third wave was conducted during the middle two weeks of April 1977.

Interview Procedures- Interviews were conducted from the 310 sampling points across the nation. Interviewers were experienced in conducting marketing and public opinion polls, although few had conducted health screenings. The interviewers were given a written explanation of the study and samples of expected responses and problems, to use in answering questions that the respondents might ask. Care was taken to probe for information about all the print handicapped individuals in each household. They were instructed to refer difficult questions from respondents to interviewer supervisors.

Using Trendex's standard operating procedures, interviewers were required to make at least three attempts at reaching a qualified

respondent in a household. Qualified respondents were defined as household members who were 16 years of age or older. Substitutions were made for non-response and incomplete interviews. For the most part, individuals identified as having a reading problem answered all of the follow-up questions. The most common exception was refusal or lack of precise information on the age of the person with the reading problem.

Treatment of Partial Responses- Partially completed questionnaires were accepted if there were enough data to render them useful (i.e., if the questions on sex and nature of problem were answered). If a respondent reported a reading problem in the household but refused to discuss it, or if the major portion of the questionnaire was left blank, the respondent was sent a letter that briefly explained the survey, and a stamped, addressed card with the screening questions on the back. The respondents were requested to answer the questions and return the card. There were 257 refusals from the two combined January waves, and 84 refusals from the April wave, giving a total of 341 screening questionnaires for which a reading disability was reported without supporting information. About 20 percent of the cards were returned, and were added to the sample. Some 273 refusals remained after this process, or about four percent of the 7,585 usable responses.

Processing the Questionnaire

Coding Procedure- The states were coded into the nine census regions defined by the U.S. Census Bureau. Hawaii and Alaska were not included in the sample. Three coding issues required special attention: inexact

ages, relationships between persons with reading disabilities in one household, and the nature of the reading disabilities.

Allocation of Inexact Ages

Despite probes, exact ages were not given by all respondents.* Vague answers such as "under 21," "in my 40's," "over 65," or "retired" were treated by assigning ages proportionate to the age distribution of persons with known ages based on the following criteria: (a) "in my ___'s"were distributed to the pertinent 10 year span--e.g., "in my 20's" were allocated evenly to the ages 20 to 29; (b) "under ___"s were distributed in the preceding 10 years span--e.g., "under 30"s were allocated to the ages 20 to 29; (c) "over ___"s were distributed in the subsequent 15 year span for the benchmark ages 10, 20, 21, 30, 40, 50, 60, 65, 70, and 80--e.g., "over 40"s were distributed among the ages 41 to 55; (d) "over ___"s were distributed in the subsequent 10 year span for non-benchmark ages; (e) "young" responses were distributed among ages 6 to 30; (f) "middle aged" responses were distributed among ages 31 to 60; (g) "old" responses were distributed among ages 61 to 97.

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*The problem of getting older persons to identify themselves as elderly is dealt with in a paper by Bultena. Here one third of a large study group of persons over 70 years old continued to think of themselves as middle See Bultena and Powers (1978).

Relationship Coding- Coding the relationships between two or more persons with reading problems in one household presented a problem because the questionnaire elicited information on the proxy's relationship to the print handicapped individual, but not information regarding the relationships between handicapped individuals (other than the proxy) within one household. In considering the problem, three premises were made: (a) Familial relationships are not defined vis-a-vis the household, but rather vis-a-vis other family members. For example, "father" denotes the existence of a son or daughter, but the same person may also be a "husband" (denoting the existence of a wife) and "son" (denoting the existence of parents). "Mother," in turn, may also be "wife," "son and daughter" are also "brother and sister," and so on; (b) These relationships are either vertical (e.g., grandparent/parent/child) or horizontal (e.g., siblings, spouses); (c) If only one family member is chosen as the base for defining relationships, then the vertical or horizontal definitions would be lost. For example, using the male head of household as the focal point, "wife," "daughter" and "son" would lose their other relationship roles as "mother," "sister" and "brother."

Each person could have more than one relationship role, depending on the number of individuals in the household having reading problems. If there were two people, they would each have one relationship role, if there were three people in the household with problems, each would have two relationship roles, and so on. Relationships were then coded by two criteria: gender (male or female) and nature of the relationship (consanguine = blood ties or affinal = marriage ties). Table 2-2 shows

the different possible relationship roles. The numbers in parentheses are the code numbers used for tabulating the data.

Nature of Problem Coding- The system used to code the nature of the reading problem was designed for both the screening and call-back questionnaires. The coding system was designed to record the relatively imprecise nature of disabilities reported through open-ended questions in the screening as well as the more complete information from the follow-up call-back. Responses ranged from information on the broad nature of the problem (physical, learning, vision), to the specific functional nature of the disability ("can't turn pages," "cannot see clearly"), to symptoms of the medical problem (headaches from accident, deformed since birth), to names for an impairment ("totally blind"). The screening questionnaires most often elicited responses dealing with the functional limitations and symptoms of the problem, whereas the call-back questionnaires provided more information on the impairment and its medical pathology. Therefore, the coding system had to be sufficiently detailed to record the full range of answers, yet flexible enough for data manipulations and analyses. In all cases, the answers were the respondents' understanding of their own or household members' problems, rather than objective medical classifications.

The nature of the problem coding system developed by AFB staff is provided in Appendix G. Because this was the study team's first experience with medical coding, the National Center for Health Statistics (NCHS) was asked to review our coding approach and manual. NCHS's

comments and suggestions were incorporated into the final coding procedures. With hindsight, the resulting coding system provided too much detail, which later had to be aggregated through data processing. This was particularly evident where respondents reported more than one problem. For example, "He inherited some brain damage which became more serious after an accident affecting his vision while playing baseball." Such responses of multiple problems were common.

The coders' training included practice with an alphabetical index of the most common answers to the nature of problem questions. All of the coded questionnaires were then reviewed by project staff to maintain consistency and completeness.

Classification of Persons with Multiple Problems- Cases of persons with multiple problems were carefully reviewed, and an assignment to a primary disability area was made. For example, in the case previously cited (inherited brain damage which became more serious after an accident affecting vision), the primary designation was to a vision problem because the affects of the brain damage were unspecified. The designated primary disability then became the basis for selecting a sample for the call-back interviews. It was helpful in this process to examine the patterns of multiple problems that were reported. A striking characteristic of the entire reading disabled group is the presence of multiple and compounding limitations. This finding reinforces the danger of equating the number of persons with reading limitations with a count of disorders.

The relative frequency distribution of reasons for non-response seem fairly comparable by disability type, varying by only one or two percent through the two waves of call-back interviews. Non-response due to disconnected phones or incorrect information averaged at ten percent; not available after repeated calls or because the respondents were too ill accounted for 17 percent; instances where the desired respondent had moved or died accounted for four percent.

Table 2-2

Relationship Coding Between Two or More Persons with Reading Problems in One Household

	1	2	3	4	5	6	7	8	9
CONSANGUINE MALE 1		Father (12)	Son (13)	Grand-father (14)	Grandson (15)	Brother (16)	Other Relative (17)		Undetermined (19)
CONSANGUINE FEMALE 2		Mother (22)	Daughter (23)	Grand-mother (24)	Grand-daughter (25)	Sister (26)	Other Relative (27)		Undetermined (29)
AFFINAL MALE 3	Husband (31)	Stepfather (-in law) (32)	Stepson (-in law) (33)			Stepbrother (-in law) (36)	Other Relative (37)	Friend (38)	Undetermined (39)
AFFINAL FEMALE 4	Wife (41)	Stepmother (-in law) (42)	Stepdaughter (-in law) (43)			Stepsister (-in law) (46)	Other Relative (47)	Friend (48)	Undetermined (49)

NO SECOND RELATIONSHIP = (00)

Treatment of Persons with Undetermined Affects- In order to deal with cases where individuals did not precisely specify the functional limitation related to their impairment (e.g., old age, poisoning, cancer), data were compiled so that it was possible to impute a broad category of limitation. This was done cautiously when a single problem was reported. For example, approximately 200 persons reported diabetes, half of whom indicated its effect on vision. Only two persons with diabetes reported motor or cognitive-intellectual disabilities as affects. The cases of diabetes with unspecified functional limitations were imputed functional limitations in proportion to the group with the same etiology/symptom that did specify a disability--i.e., approximately 98 percent vision disabilities. About 35 percent of the cases with undetermined affects were handled in this manner. This amounted to six percent of the total 7,585 cases.

Projection of Screening Results to the Nation

July 1977 U.S. Bureau of the Census estimates of housing and population were used to project the survey results to the nation.* Our sampling fraction was 1/348 of the nation's households.

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*U.S. Department of Commerce, Bureau of the Census, Current Population Reports, Population Estimates and Projections, Series P-25, No. 725. (1978). U.S. Department of Commerce News, CB78-13 (1978).

Sampling fractions were calculated based on the nine census regions and the four age groups. For example, 1,643 persons were identified in the East North Central region as having reading disabilities. To obtain the projection for this region, the number of households in the region (13,900,000) was divided by the number of households screened in the East North Central region in the three omnibus waves. The region was then subdivided into the four age groups, and compared to the census sample. This ratio was multiplied by the size of the identified group, yielding a projection of about 521,000 persons after rounding.

MEASUREMENT ERRORS

Overreporting

In our indentification process, the screening questions may have overestimated or underestimated the population of persons with disabilities in reading regular print. In addition to measurement errors commonly called false negatives (persons not identified as disabled who have real limitations), there is also the problem of false positives (persons identified as disabled who have no meaningful difficulties). In any study like ours, where persons may be reluctant to be identified, the risks of overidentification are much lower than the risks of underreporting. False positives could always be screened out in the Phase II call-back interview and reclassified as not having reading problems, whereas those persons who were incorrectly classified as having no disabilities in the screening could never be accounted for at a later stage.

Verification or validation of the screening information was undertaken by call-back interviews in 4004 cases. It is not possible to

estimate precisely the extent of false positives among the screenings because persons identified on the first calling might have chosen to deny these disabilities on reinterview as a way of graciously refusing to participate in a lenghty interview. This was especially a problem where the information may have been obtained from one respondent on the first call and a different respondent on the call-back.

Despite a preference for speaking directly with the persons with the reading problem (except in cases where these persons were unable to answer for themselves: the under 16 group plus persons too ill or disabled), cost and time constraints did not always allow us to be that selective. It was also not clear whether information provided by different proxy respondents would not have been more accurate for verification than talking to the impaired individual him/herself. Notwithstanding, all these factors, false positives identified in this way appear to be on the order of ten percent. Persons reclassified as "not disabled" were excluded from the follow-up interviews.

A substantial number of persons (8%) said that they did not have a reading problem at the outset of the call-back interview, prior to being asked the screening verification questions. Although it is possible that they reflect unreliability in the original measurement, it was our sense that this group essentially may have been refusing to participate under another guise. The rate was essentially invariant across reading disabilities initially reported in the screening.

Some 13 percent of the households did not report a disability after being asked a set of verification questions. This percentage was lowest (4%) for the learning group which was largely responded for by proxies, and highest (15%) for persons who initially indicated vision

problems in the screening. We wondered whether we should eliminate this segment of the sample, which might be false positives, from the screening survey, but decided instead to report these findings and allow the reader to eliminate them if he/she wished. (See Table 2-3 for reasons for nonresponse in the call-back interviews.)

It is possible to read the data on verification or validation rates as either encouraging or discouraging. Our preference is to be positive about the results by comparison with findings from recent Bureau of the Census* studies concerning the reliability with which persons report their disability status. To support its decision to exclude a series of questions on disability in the 1980 census, the Bureau demonstrated that 38 percent of households reporting work/activity/transportation disabilities in its pretest mail survey of July 1976 reported that the household did not have any members with disabilities in a second personal interview survey in September-October.* In addition, 37 percent of the households that reported work disabilities in September-October had not reported disabilities in the July mail survey. Part of this inconsistency undoubtedly is due to different interview techniques used by the Bureau (mail, personal interviews) and to the acceptance of reports by different people in the household for the two periods.

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*U.S. Department of Commerce, Bureau of the Census, memorandum prepared by T. McNeil and D. Slater (1978).

Table 2-3

Percent Distribution of Reasons for Non-Response at Outset of Call-Back Interview*

Reasons	Percent All	Physical	Learning	Vision
Respondent refused (not interested, didn't want to be bothered)	27	24	10	30
Family member refused	21	21	49	17
Not available, too ill, no answer after several tries	17	17	15	18
Disconnected phone, incorrect information or telephone numbers	10	9	11	8
Interviewer terminated after asking screening questions	13	13	4	15
Respondent said no reading problem at outset (prior to asking verification questions)	8	9	9	9
Deceased, moved	4	6	3	4
TOTAL =	100	100	100	100
Sample Size n =	(1,845)	(393)	(240)	(1,094)
Non-Response Rate =	47	44	34	51

*Includes 118 undeterminedes.

Underreporting- A more troublesome issue than false positives for our study was underreporting, or false negatives. For example, in about four percent of our identifications, a household indicated a disability in reading regular print, but refused to discuss it or participate in a follow-up survey that sought to verify the household's initial response. These cases were excluded from the positive identifications and were not used in the national estimates, but could easily have been false negatives.

Potential sources of underreporting have been reviewed in several studies prepared for the National Center for Health Statistics.* The findings appearing most relevant for this study are:

1. Social Embarrassment of Disabilities

   It may be that physicians are not fully informing their patients of the precise nature and seriousness of their conditions, or these may be a significant number of latent undetected cases. Nevertheless, there appears to be a significant and predictable relationship between the personal threat or social embarrassment that the condition holds for the respondent and the accuracy of the report. Based on comparisons of reported conditions and medical records, it can be shown that the less socially

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*National Center for Health Statistics, Vital and Health Statistics Series 2, No. 69 (1977). See also Mechanic (1966); Segall (1976); Verbrugge (1976); Seeback (1977); and Nathanson (1977).

acceptable the diagnosis is for the respondent, the higher the probability that he/she will misreport the seriousness of the condition, or fail to report it at all. For socially acceptable conditions like heart disease or asthma, reporting seems to be fairly accurate and complete. But for mental and personality disorders and some diseases such as venereal disease, underreporting is marked (up to 75%) and these biases can result in misleading conclusions. Although the direction of error is usually toward underreporting, overreporting can be significant as well.

2. Education, Income, Age, Sex

The effects of age, education, sex, and income of the respondent on underreporting are present but not strong. Persons with higher education and income but lower ages tend to report chronic conditions less accurately. Also, the accuracy and completeness of reporting have been found in some studies to be substantially higher among women than among men 65 years and older. These reporting inconsistencies may be due to several factors, e.g., disorders may be less socially acceptable among a particular group, or poor health and accompanying disabilities may be more prevalent among the lower socioeconomic groups.

3. Proxy Respondents

The effect of using proxy respondents to report health information for family members is unclear. Perhaps due to a lack of awareness or concern, reporting is poorer when provided by respondents whose relationship is distant from the person about whom

the information is being sought. Underreporting by a parent or spouse is more common than by the person with the problem.

A variety of techniques are now used to reduce measurement errors inherent in survey research. A careful structuring of questions to permit probes allows the respondent to comfortably say yes or no, avoids leading the respondent to a desired answer, etc.,has developed over the years. The telephone screening interview, which took about a minute in a lengthy omnibus survey is especially susceptible to both false positives and negatives. But on the other hand, it may provide the kind of non-threatening atmosphere that would yield high returns. This issue needs further research.

CHAPTER THREE

METHODOLOGY FOR THE CALL-BACK STUDY

As a matter of policy, it was preferable to utilize an interview medium that the largest portion of the sample would be able to respond to without assistance. Personal interviews were preferred, but could not be afforded. Performing the follow-up interviews by mail was considered, but recent studies conducted by NLS/BPH (Nelson Associates, 1969; GSS, 1974) showed response rates to mail questionnaires among visually and physically handicapped users of NLS/BPH services in the range of 17 percent to 40 percent--a rate lower than that desired. Hence, our choice was to conduct the survey by telephone.

A total sample of 2,000 completed call-back interviews was desired.* No guidelines could be found in the literature for response rates in interviewing persons with disabilities, using telephones as the interviewing medium, but a 50% completion rate was considered reasonable. We decided to interview only one disabled person from a household irrespective of the number of household members with reading problems. Hence, a sampling frame of 4,000 was needed.

SELECTION OF THE SUBSAMPLE

Subsamples for the call-back interviews were selected from the screening waves as each wave was completed (in January and April 1977). Persons identified as having a reading disability from the January 1977 screening waves were pooled as a matter of convenience

*Based on desired precision of estimates. See Sudman (1976).

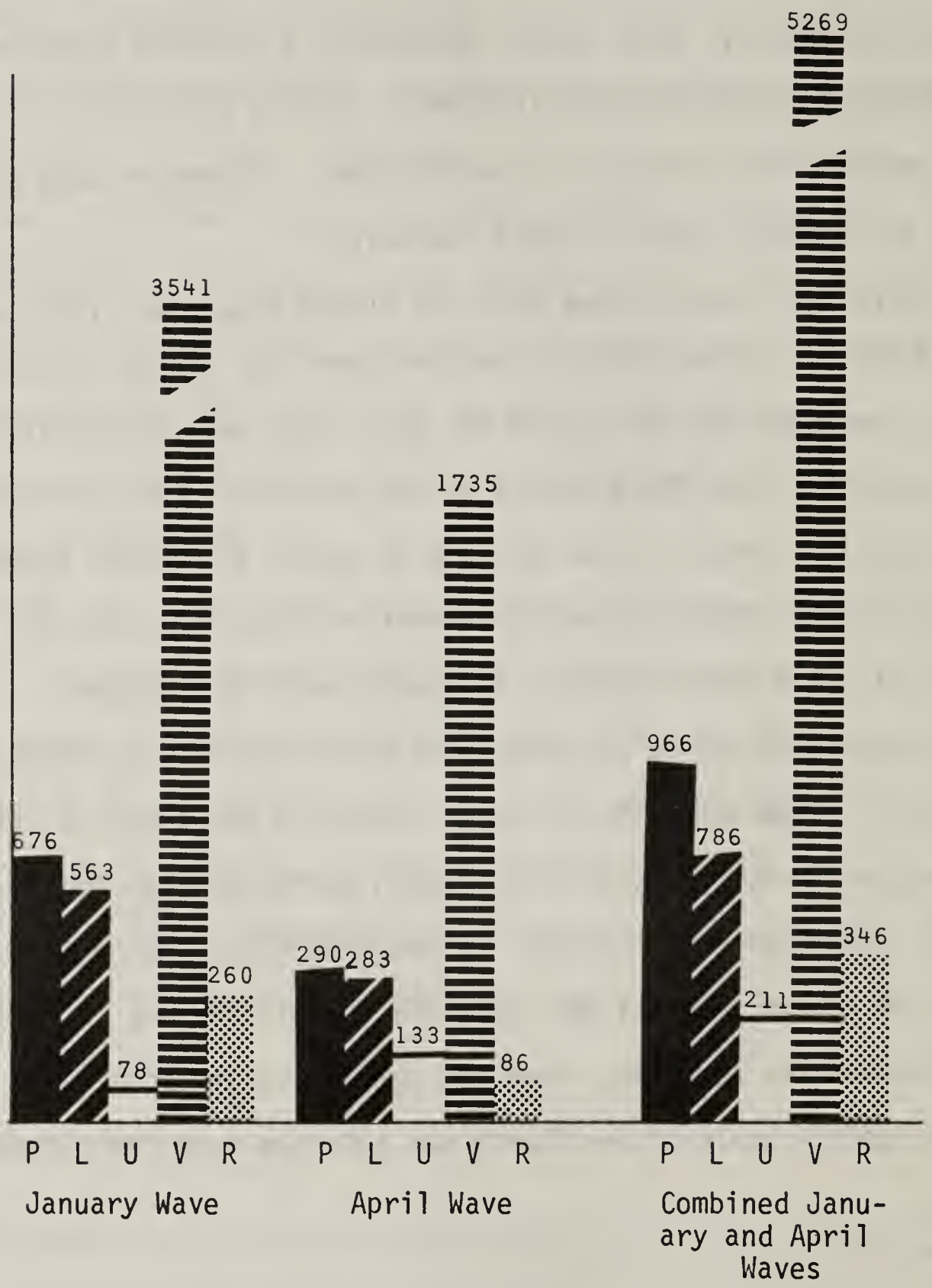
in drawing a subsample. The frame for the January subsample contained approximately 4,500 screening questionnaires: the frame for the April subsample contained about 2,500 names. Both sampling frames were divided into four groups representing the primary reading disability reported by the respondent. These four disability groups were: Learning Physical (Dexterity, Motor and/or Weakness), Vision and Undetermined. Cases where the household had reported a reading disability for one of its members, but refused to provide other information were put into a fifth group loosely termed "Refusals."

Figure 3-1 clearly shows that the Vision grouping (5,269) was two and one half times larger than the other four groups (2,310). In order to maximize the utility of the data that could be obtained in call-back interviews for analysis of the characteristics and needs of each disability group, it was decided to sample all of the respondents in the Learning, Physical, and Undetermined groupings, but only a portion of the Vision grouping. Refusals would be excluded.

Persons with vision problems were then classified by three other criteria: 1) age group (6-16, 17-44, 45-64, 65 and over), 2) geographical region (Census regions of Northeast, North Central, South, West), and 3) community (metropolitan, nonmetropolitan). Owing to the small size of the youngest age group (6-16), all persons in this group were selected for sampling. From the January Vision screens, a systematic random sample of one fourth was selected from the three older groups.

Figure 3-1

Distribution of Screening Questionnaires into Five Major Nature of Problem Groupings



KEY: P = Physical, L = Learning, U = Undetermined, V = Vision, R = Refusal
(Dexterity, Motor, and/or Weakness)

A total sample of 1,997 persons were selected in this manner for the first wave of call-back interviews. The completion rate on this wave was 49 percent. Hence, to meet our target of 2,000 completed interviews, the entire group of 2,300 screening questionnaires obtained from the April wave was utilized for the second set of call-back interviews.

Figure 3-2 shows the resultant sampling and completion distributions for the four disability groups.

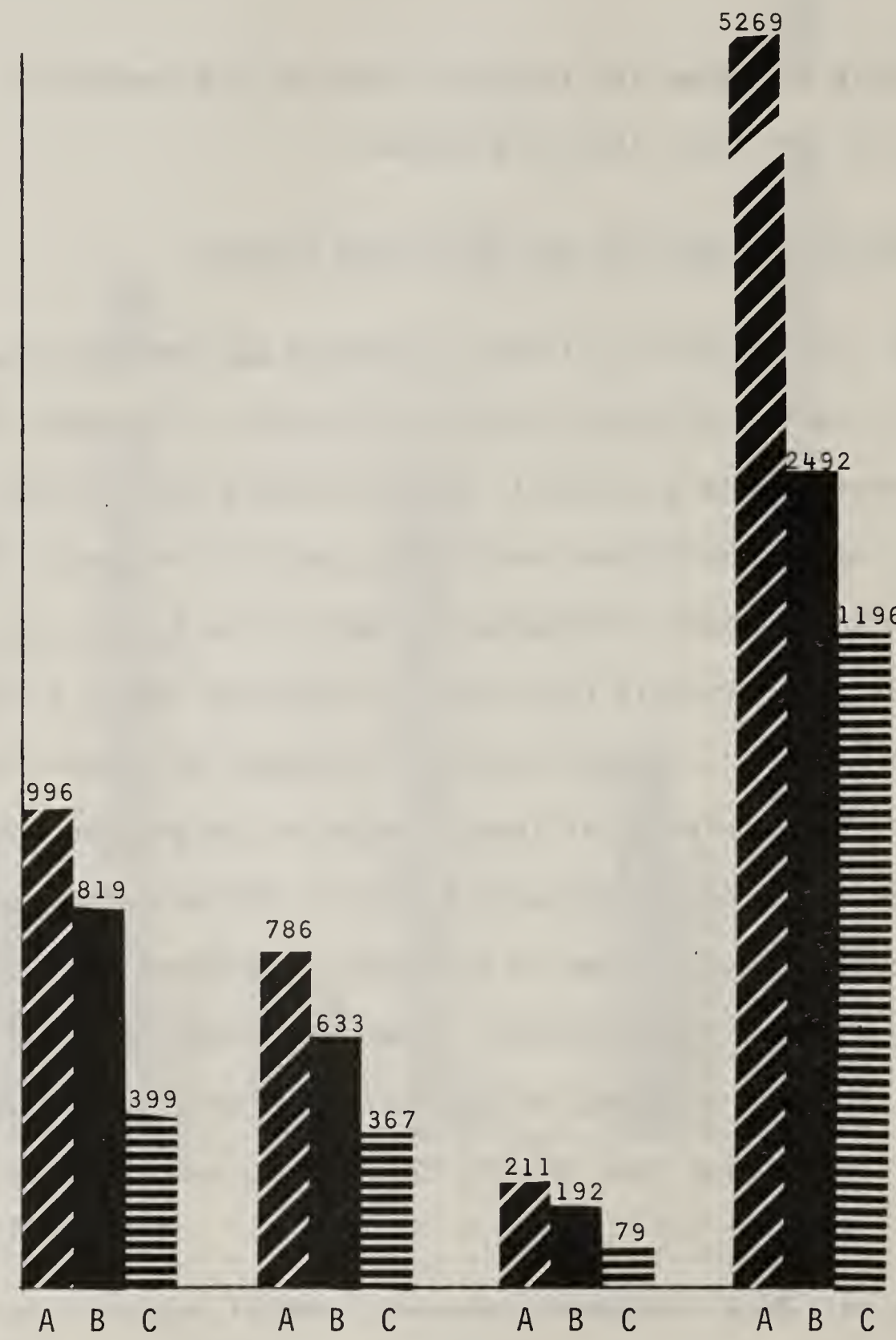
QUESTIONNAIRE PREPARATION AND PRETESTING PROCESS

The initial draft call-back instrument was prepared after examination of a variety of readily accessible studies. Personal interviews were conducted with individuals who had reading disabilities, with reading and rehabilitation specialists, and with regional librarians in the NLS/BPH system. (Josephson's study on the Social Life of the Blind was a particularly rich source of question issues.) As noted in Volume 2, there is not much current literature on studies of reading habits of the population at large. Owing to the project schedule, an extensive search of questionnaires used in related prior studies could not be accomplished in time to incorporate pertinent questions and use the same wording. Nevertheless, it was reassuring to find that the survey instrument prepared for the 1977 study on U.S. reading habits conducted for the the Book Industry Study Group contained many similar items.

The call-back instrument underwent several revisions before it was ready for pretest. An early draft of the questionnaire was sent out to

Figure 3-2

Distribution of Questionnaires Intended for Call-Back Sampling Into Four Reading Problem Categories



KEY: A = Total Screening Questionnaires, B = Sample Used for Call-Back Interviews, C = Completed Call-Back Questionnaires

approximately 250 regional librarians, disability groups, social scientists, and other technical consultants for their review and comments. The draft of the instrument informed many of these people and their organizations that a survey was proceeding which might ultimately affect the services which they might deliver or receive. This was a particularly worthwhile procedure since over 75 percent of the recipients of the draft questionnaire returned valuable comments and suggestions. Mindful of the mission of the study, the National Library Service also diligently examined each question and made its recommendations for substance and wording. Each suggestion was carefully reviewed in the revision of the instrument. A second draft was then reviewed in a lengthy face-to-face session with the Chief of the NLS/BPH and his key staff. This robust interchange was a most healthy process,as it further clarified for the study team the sponsoring agency's concerns and objectives. After approval had been given by NLS/BPH, the survey instrument was ready for pretest.

For the pretest, it was decided to obtain lists of persons with known disabilities in using regular print from agencies of and for persons with specific disabilities. It was hoped that these persons would participate in the lengthy version of the pretest questionnaire, and would offer specific and useful comments. Several disability groups and agencies cooperated by fully explaining the purpose of the survey to the potential respondents and asking whether they were willing to participate in an interview.

In this manner privacy was preserved, time was not wasted in needless call-backs to find desired respondents, and proxy interviews were

limited. Table 3-1 provides a list of the disability groups that assisted by supplying names for the pretests.

Respondents used for the pretests all lived in the New York metropolitan area to avoid telephone toll charges. Interviews were conducted during the hours of 7 and 10 p.m., and lasted from 45 mintues to an hour and a half. Approximately 100 pretest calls were made from the Trendex Central office in Westport, Connecticut; each call was monitored by AFB project staff. At the end of each evening, a discussion was held between interviewers and the project staff concerning problems in wording, difficult skip patterns, and in general, questions that did not seem to work. The interviewers offered many useful suggestions. The changes made as a result of the pretests included simplification of the layout of the questionnaire, changes in the wording, elimination of extraneous questions to reduce the interview length, and preparation of a briefer introduction. This proposed final version was again submitted to NLS/BPH. After some minor modifications, this version was approved by NLS/BPH and prepared for distribution to field interviewers.

INTERVIEWING PROCESS

Selection/Training of Interviewers

A detailed interviewing manual was prepared and given to each of the interviewers. This provided information about the survey and the NLS/BPH Talking Book and Braille program, and gave samples of the materials available to disabled readers (flexible discs, Braille Book

Table 3-1

List of Disability Groups Providing Respondents for the Pretest Interviews

National Multiple Sclerosis Society
National Muscular Dystrophy Association of America
United Cerebral Palsy of New York
Association for Crippled Children and Adults of New York State, Inc.
Local Chapter of the New York State Association for the Help of Retarded Children
Association for Children with Learning Disabilities
The Industrial Home for the Blind, New York, N.Y.
New York Association for the Blind, New York, N.Y.
Jewish Guild for the Blind, New York, N.Y.

Review, Talking Book Topics). The manual also pointed out areas that might give problems during the interview, and gave suggestions on how to overcome these problems. Funds were allocated to interviewer training time as a way of encouraging interviewers to follow instructions, to study the questionnaire carefully and thoroughly, and to conduct practice interviews with family and friends before performing the actual telephone interviews.

About 280 interviewers were selected to perform the call-back interviews, based on the geographical distribution of selected respondents, the availability of the interviewers, and the quality of their interviewing in previous surveys. Each interviewer was given a minimum of three and a maximum of ten questionnaires to complete: on one hand,it was felt that a larger number interviewers would minimize interviewer effects, and on the other that experience in working with the instrument was essential in obtaining thorough and accurate responses. Every household was to be given as many calls as were needed to complete an interview. If after three calls the desired respondent was still unavailable, a proxy respondent was accepted. Proxies were required if the desired respondent was under 16 years old or unable to use a telephone.

Interviewers were instructed to probe for complete answers to the open-ended questions and to record all information exactly as given by the respondent.

Characteristics of Interviews

The first wave of the call-back interviews was performed during the last two weeks of March 1977, and the second wave during the first two weeks

of June 1977. Interviewing was generally performed between the hours of 7 and 10 p.m. on weekday evenings. The interviews averaged about 50 minutes: the shortest completed questionnaire lasted 25 minutes, the longest lasted 2 hours and ten minutes.

The two interview waves were accomplished in a similar manner. Most of the interviewers for the second wave had conducted the survey in the first wave, and thus were already experienced in using the questionnaire. For the second wave, respondents were not asked in advance to indicate by post card their preferred time for an interview; this procedure actually seemed to expedite the interviewing process.

The interview covered many areas in considerable depth. For example, to meet NLS/BPH's need for detailed information on reading interests, it was necessary to obtain responses to specific items on several lists. The interview consequently was quite long for many households. The time factor was of concern particularly for the elderly, who found it tiring to sit through the entire interview. Some interviewers devised a system whereby they would complete half the interview in one evening, then fix an appointed time to complete the second half the following evening.

Most respondents responded very positively to the questionnaire: interviewers frequently reported difficulty in cutting off lengthy explanations and keeping the interview moving. The respondents enjoyed the chance to talk about themselves. The questions were not prying, yet they yielded ample opportunity for the respondents to expound to

any degree they wished.

Use of a Letter to Encourage Participation in the Call-Back Survey

As noted, the call-back interviews were done in two waves, following closely upon the initial screening interviews. The first wave of call-backs was delayed until about three months after the initial interview because of the need to finalize a pretested and approved questionnaire from the NLS/BPH, and to fit into the work schedule of Trendex. One of the pretest findings was that the most common point where refusals occurred,in cases where prior approval with a disability group had not been obtained, was at the end of the introductory remarks. This caused us to wonder whether we could reduce refusals and the length of our introductory remarks by alerting the respondent and his/her household in advance to expect a call.

It was hoped that an introductory letter explaining the research, assuring anonymity, appealing for help, and stressing the social utility and potential personal benefit to the respondent, might encourage the reader and his family to participate.* The use of incentives or rewards for participation was considered, but was deemed unnecessary. The factor of family participation in the study cannot be overstressed, since many disabled persons are dependent on household members for assistance in activities of daily living, including reading. In our

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*Dillman, Fallegos, and Frey (1976).

survey, where the interviews of the 6-16 year old age group were to be completed by parents or other family, household cooperation was essential.

Hence, respondents selected for the first wave of call-back interviews were all sent an introductory letter which described the purposes of the study and requested participation in an upcoming telephone interview. A fact sheet about the Talking Book and Braille Program was enclosed, as well as an application for the service. The fourth enclosure was an addressed, postage-paid postcard, on which the respondent was asked to indicate the most convenient time for him/her for the call-back interview.

In view of the many refusals obtained, the effect of the letter on response rate was unclear. It became questionable whether it was worthwhile to delay the start of the call-back interviews for the mailing of introductory letters and the receipt of prepaid postcards indicating the time and day of preference for an interview.

Table 2-3 shows reasons given for non-response in the call-back interviews and provides the validation data for the screenings. Overall, a non-response rate of 47 percent was attained. Slightly under half of these 1,245 non-responses were due to outright refusals by the respondent (27%) or a family member (21%). In most of these cases, the respondent said he/she was too busy or didn't want to be bothered and did not wish us to call back at another time.*

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*It was not clear whether we should have tried to recontact these refusals through persuasive letters and call-backs in hopes of getting a different

For the second wave, it was decided to test whether a letter providing information legitimizing the survey made a significant difference in alleviating tensions and uncertainty--i.e., improved the response rate for this special population. The sample for the second wave of call-back interviews was randomly divided into three groups of equal size. The first group received a letter similar to the one sent to the respondents of the first wave of call-back interviews, a fact sheet and an application, but no postcard. The second group received a briefer letter, without an application or fact sheet. The third group received nothing at all.

Response Rates for Call-Back Interviews

Figure 3-3 shows data on response rates for the first wave interviews, and interviews in the second wave with three different treatments. The findings showed there was essentially no difference in response rate; if anything, the rate was improved slightly (by .4 percentage points) by not giving prior warning of an interview.

Some quite distinct variations in non-response rates are seen by stratifying the non-respondents into three disability types--physical (holding/turning), learning, vision (seeing). Non-response in the older group of persons with visual problems was greatest, nearly 51 percent. Non-response by persons with physical problems was somewhat less, 44 percent, and lowest in the learning group--34 percent.

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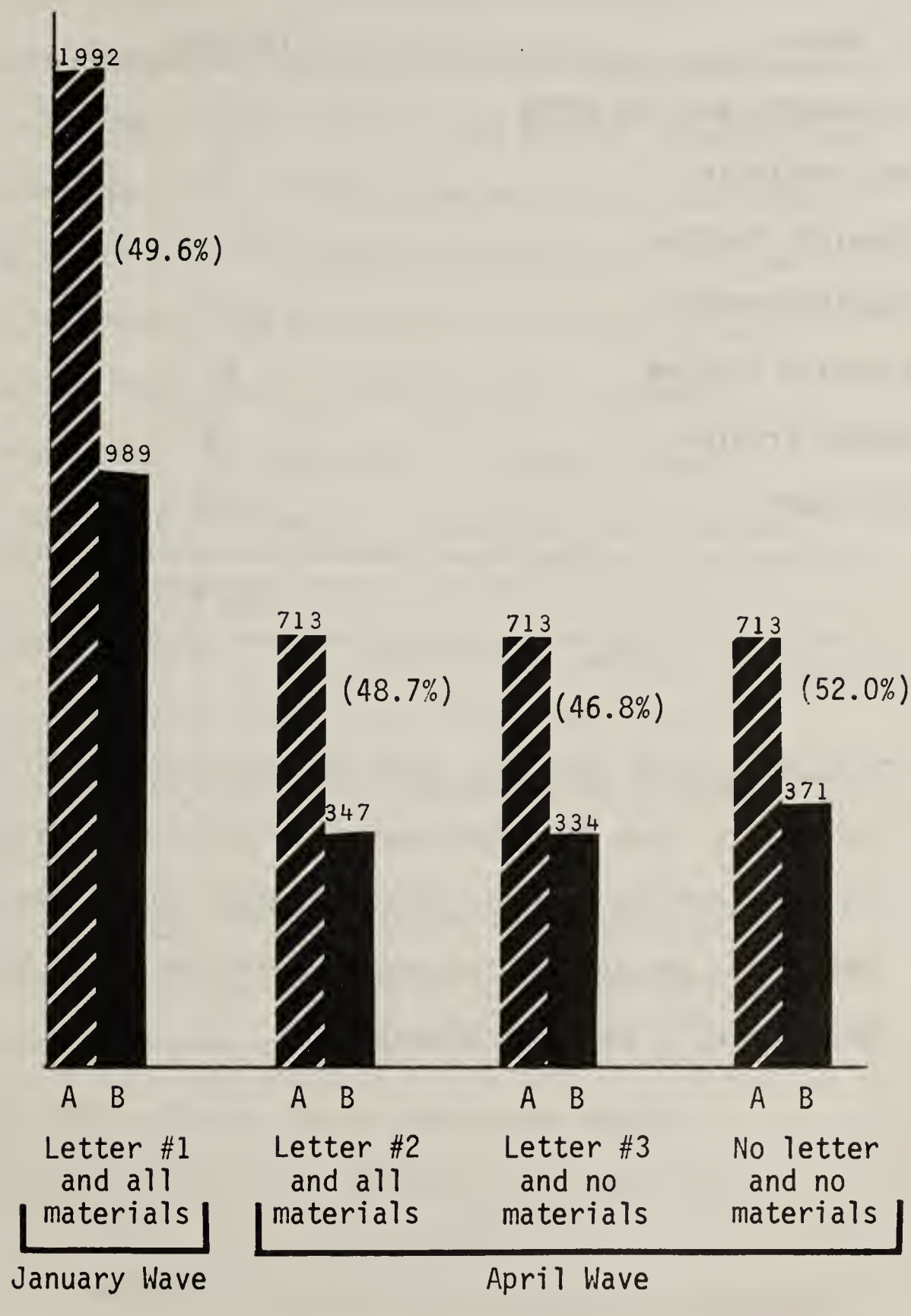
person on the phone. Since a number of attitudinal and personal questions were on the survey, we took a refusal to indicate that response to the 60 minute survey would be poor.

Figure 3-3

Responses and Response Rates for the Four Ways of Mailing Introductory Literature



KEY: A = Sample Used for Call-Back Interviews, B = Responses

Call-back Interviews with Proxy Respondents

Interviews were conducted with household members other than the desired respondent in 32% of other cases. The reasons for the proxy interviews are arrayed in Table 3-2.

Table 3-2

Reason for Proxy Interviews

Reason	Percent
Respondent was too young	24
Not Available	18
Physical Problem	17
Hearing Problem	11
Learning Problem	11
Speech Problem	5
All other	14
	100 %

n = 652

The main reasons were age, unavailability and medical condition. For example, very few interviews were conducted with persons who were confined to their beds. In about 20% of the proxy interviews, the desired respondents participated in the interview with the proxy respondent.

Interviewer Comments

The interviewers were fairly positive about the outcome of the survey and the interview process. They reported that over 88% of the respondents were very cooperative, and a two percent were uncooperative or hostile. The interviewers felt that 59% of their respondents enjoyed the interview very much, 38% moderately enjoyed the interview, and four percent did not enjoy the interview at all. Proxy respondents tended to enjoy the interview slightly less as did persons whose attitudes were relatively negative. Fourty nine percent of the respondents found the interview to be very interesting, 42% were moderately interested, and 8% were not at all interested. These statistics show that on the whole the respondents were concerned about the survey and its central issues. There were not major differences by age, sex, race, region, education, living situation, major activity, reading disabilities, or attitudes of the respondent or whether the interview was conducted with a proxy respondent. Healthy respondents, who were more mobile, tended to be slightly more co-operative.

The interviewers reported that the respondents were generally conficent (88%) and happy (86% respectively), and relatively few seemed depressed (15%) or very lonely (12%). Most people talked freely about their medical problems and disabilities, and the way their disabilities affected their lives. There was a definite feeling among the respondents that they wanted to help and improve themselves, and were searching for ways of doing this.

Validation Procedures

When the questionnaires came back from the field, they were carefully reviewed by Trendex Central staff to eliminate incomplete and partially complete questionnaires. Verification checks were also made by recalls to ensure that the information obtained was accurate. In this validation procedure, seven percent of the completed questionnaires were randomly selected and recalled from the Trendex Central office. The respondent was asked two questions from the opening section (on reading disability and knowledge of the NLS/BPH program) and two questions from the last section (on education and income). The answers from these spot-checks, compared with those given on the original interview, indicated that the interviews had been completed fully and accurately.

Editing and Coding the Interviews

Preparation of the Coding Manual- One of the most difficult and important aspects of this component of the survey was preparing an adequate code book to categorize the data and set up data files. The instrument was predominantly precoded; however, the few open-ended questions produced widely diverse answers. Classifications were devised by AFB project staff to record all usable data. Wherever possible, the same codes were used for similar questions to maintain consistency and to facilitate data processing.

A major coding issue for the call-back questionnaires was appropriately categorizing the nature of the respondents' reading disabilities. In devising the coding scheme for the screening questionnaires, it was kept in mind that the same types of responses--symptomology, pathology,

and etiology--would have to be classified for the call-back questionnaires. Thus, one coding system was developed for both surveys.

The Coding Process- Editing and coding were performed by Trendex. Ten skilled and experienced coders were used. Training sessions were held with the coders by AFB project staff and a member of the Trendex staff who had been involved in the creation of the code book.

Due to the length of the questionnaire and the coding manual, it was divided into three distinct units for coding. In order to limit errors and reduce inconsistency due to coding style differences, a small group of coders was responsible for coding one of each of the three units. This system allowed the coders to become very familiar with a small section of the questionnaire, which in turn facilitated the coding process. The coding process was monitored by Trendex supervisory staff, and AFB project staff were available to help code the more difficult open-ended items and to answer questions. Coded questionnaires were reviewed in their entirety by a coding supervisor and spot-checked by AFB staff.

Cleaning the Data- The coded questionnaires were key punched and verified by a sub-contractor to Trendex, and the cards were turned over to AFB for data processing. The data were transferred to magnetic tape for cleaning. The cleaning process involved a combination of computer checking to locate mistakes, and direct referral back to the original questionnaires to correct them. Three types of errors were searched for: 1) logical card sequencing, to ensure that all necessary

keypunch cards existed for every questionnaire, and no data set contained duplicate cards; 2) logical question sequencing, to ensure that proper skip patterns were maintained, that no questions were completed where they should not have been, and that all questions were completed when they should have been; and 3) out of range checks to ensure that no variable values were coded or keypunched incorrectly.

Three cleaning runs were made, until the errors had been eliminated.

Weighting the Call-Back Samples

To facilitate analysis, the call-back data were weighted to the size of the target population that had been identified in the screening interviews. In this way, it was easier to make projections to the nation by merely inflating the weighted data by the screening proportion (1/348).

The weighting process followed the standard methods described by Kish (1965). It consisted of two components:

1. The stratified samples by disability type and age (of unequal proportions) were weighted by the reciprocals of their original sampling proportions.
2. An adjustment was made for differential response rates in sampling the different disability and age strata.

The weights for each of the strata are given in Table 3-3.

Table 3-3

Weights for Projecting Call-Back Sample to Size of Screening Population*

Primary Disability In Screening	Number of Completed Interviews In Call-Back	Age Group 6-16 Years	17-44 Years	45-64 Years	65 Years & over	Average Weight
Seeing	1,196	2.1351	4.1925	5.1112	4.5500	4.4056
Physical	399	2.1138	2.1138	2.4768	2.6422	2.5589
Learning	364	1.9390	2.1872	2.7543	5.9020	2.1417
Undetermined**	79	2.4467	2.8984	3.5372	2.3631	2.8753
Total	2,038					

*Rates of number of persons identified in screening to number of completed interviews.

**Assigned to appropriate disability in call-back.

CHAPTER FOUR

METHODOLOGY FOR INSTITUTIONAL STUDIES

A survey of institutions presents a research setting different from that of a direct survey of household residents. Just as the disabled individual must be viewed in terms of the family unit -- with its composite socio-economic condition, life style, and attitudes -- a study of residents in institutions requires an understanding of the institutional organization itself. Responses must be interpreted in light of the institution's staff, policies, services, licensed status, and its residents. These factors reflect upon institutional variation in sponsorship, regulatory system, size and geographical location.*

DEFINITION OF THE SAMPLE

The potential sampling universe of United States institutional settings sweeps broadly across different types of residential facilities and encompasses approximately six million persons in hospitals, mental institutions, nursing homes, homes for the aged and handicapped, schools for the deaf, blind, mentally ill and/or psychiatrically needy, homes for the elderly, unwed mothers, foster children or court wards, military installations, and prisons.

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*For consideration of some of these factors, see, for example, Gottesman (1974); and Winn (1974).

Some of these facilities offer services for short duration (clinics, day centers) while others provide long-term care. Many institutions include combinations of residential and outpatient services.

Recent research leads one to surmise that persons having disabilities in reading are found in nearly all of these settings, and that their prevalence rate is higher than that for the population at large. For example, Westat , Inc. (1976) estimated that nearly 150,000 persons with severe visual handicaps reside in a wide variety of institutions. This indicates a prevalence rate of severe visual impairment approximately ten times that of the general population. National statistics also demonstrate that institutions contain a significantly higher proportion of residents with severe physical disabilities than households. For example, the Bureau of the Census estimates that in 1976, 12% of the residents of long term care institutions were confined to their beds and 15% were confined to their rooms: 72% of the admissions were for medical reasons.*

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*U.S. Department of Commerce, Bureau of the Census, Current Population Reports Series P-23, No. 69 (1978). See also, National Center for Health Statistics Vital and Health Statistics Series 13, No. 27 (1977); National Center for Health Statistics Vital and Health Statistics Series 13, No. 29 (1977).

Therefore, it was decided to:

1) narrow the field of institutions to those predominantly involved in some aspect of service to individuals who have physical impairments;
2) treat the institution rather than the individual as the basic sampling unit, and obtain global information on the prevalence of reading disabilities and characteristics of institutions and residents largely from institutional staff;
3) supplement the information supplied by institutional staff with several personal interviews with residents.

Since hospitals and nursing homes (including skilled nursing and intermediate care facilities, board and care homes, extended care wings of hospitals) serve the largest portion of the target population of institutionalized persons with limitations in reading print, it was judged that such a sampling frame of these two institutional types would provide a comprehensive view of institutional use of the NLS/BPH program. Several schools for the blind and physically handicapped and rehabilitation centers were also included.

Two survey methods used to collect the desired information were:

1) Mail Survey-A six-page instrument containing forty questions to be answered by institutional staff;

2) Site Visits - Personal interviews to institutions in seven geographically dispersed states. In each of these states, approximately six to eight institutions were visited, and interviews were conducted with administrators, staff and residents.

In both surveys, questions were included about the nature of the people served (i.e., their physical and demographic characteristics), the general services of the institution, and the availability of NLS/BPH services. The mail survey used closed-ended questions with more emphasis on services and numbers, while the site visits observations and interviews were mostly open-ended and process-oriented.

MAIL SURVEY OF INSTITUTIONS

Sampling Procedure

Numbers Selected - In 1976, there were about 20,000 health care residences and 7,000 hospitals in continental U.S.* Based on this population size, 1,500 institutions were felt necessary to allow for meaningful comparisons by a few stratifying variables. A reading of the literature indicated that a rate of 25% could be considered as fairly good for institutional response.

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*U.S. Department of Commerce, Statistical Abstract of the United States-1978 (1978), p. 108.

Such statistics suggest the importance of surveying individual residents from many types of institutions to develop an understanding of potential NLS/BPH program users and institutional characteristics impacting on their patterns of use or non-use. However, after exploring the implications of such a complex and comprehensive institutional sample, it was clear that the numbers that would have to be included for a meaningful analysis of each institutional type were too expansive for the scope of this project's budget or time frame.*

Given these parameters, a national probability sample of approximately 4,000 institutions was drawn from two sources: the National Center for Health Statistics Master Facility Inventory**

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*Personal visits or direct phone calls to a large number of residents were not feasible due to the overall health conditions of residents/patients as well as the time and effort such calls might place on institutional staff who were needed to comply. A large scale on-site screening of reading disabilities from patient charts and follow-up with the eligible users was similarly deemed inappropriate due to the costs, variables regarding length of stay, and possible incompleteness of medical records.

** The National Center for Health Statistics (NCHS) Master Facility Inventory (MFI) Survey for 1973 was used to select a sample of health care residences. The MFI lists approximately 24,000 licensed nursing homes, extended care facilities, retirement centers, convalescent homes, homes for the aged, shelter care or custodial care homes, orphanages, residences for the physically handicapped, and health care units of state schools for the blind, deaf, and/or physically handicapped. Basic information on facility name, address, phone, location, size, and general levels of care is included in the computer tape version of the MFI available to the public, which AFB obtained.

National Center for Health Statistics, Inpatient Health Facilities as Reported from the 1973 MFI Survey, Vital and Health Statistics Series 14, no. 16.

(MFI) of health care residences for 1976, and the 1976 American Hospital Association (AHA) Directory.*

These two sources provided the most comprehensive and up-to-date listing of U.S. health care institutions at the time of the study. They also provided background information which was used to select facilities in proportion to sponsorship (governmental, non-profit/voluntary, private/proprietary); size of facilities (small, medium, large) and distribution by state.

To reduce the likelihood of selecting facilities that were closing(for which survey response seemed unlikely), two types of facilities were excluded from our sample: facilities with fewer than six beds, and facilities that listed a bed capacity of more than twice the 1973 average occupancy. The latter usually indicate a very low rate of occupancy often associated with unstable management structure.

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* Unlike the nursing home industry, which is loosely organized into groups according to sponsorship, hospitals form a strong association which gathers comprehensive information on both member and non-member facilities. Consequently, although the latest MFI (for 1973 data) for hospitals was obtained from NCHS and used for the generation of mailing labels, it was found more convenient to select hospitals from the 1976 edition of the American Hospital Association Guide to the Health Care Field. The AHA directory lists both surgical and non-surgical institutions. This annual listing generally parallels the MFI file with the following exceptions: facilities of less than six beds are not listed, listings are by city, and more extensive information is provided on levels of care, services available, sponsorship and occupancy. The list for 1976 includes 7,156 hospitals with a total of 1,466,000 beds.

Implications of using the MFI to Select Health Care Residences - The version of the MFI available at the time of this study had several limitations. First, it is based on data collected in 1973, and many changes in institutional existence, address, and size have subsequently occurred. Second, the MFI does not clearly describe an institution according to bed capacity and levels of care offered.* Taken together, these factors indicated that a) the initial mailing had to be large because of the likelihood that a number of institutions would have ceased to operate; b) newer facilities would be missed simply because they were not listed in the sample frame; c) stratification on the basis of institutional size was prone to error due to possible expansion since 1973 and the documented tendency over the past five years of smaller nursing homes to close.

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* Levels of care refer to licensing for different types and degrees of service (skilled care vs. custodial care, for example). Distinctions among various levels of care can provide a basis for grouping people and facilities according to a general measure of their needs and services. With these data missing, stratification by level of care could not be performed. Furthermore, some facilities separately name each level of care as though it is a separate unit; others include multiple levels of care under a single general heading. The U.S. Dept. of Commerce (1978) collected data in several categories that are responsive to problems of categorization and levels of care; subsequent research in this area should be greatly aided by the improvements they have made.

The sample of institutions drawn from the MFI listing includes a predominance of geriatric facilities. Wherever possible, using available classification codes, facilities designated as orphanages, homes for unwed mothers, foundling homes, and others not likely to make significant use of the NLS/BPH program were excluded. A few of these facilities (not coded on the MFI as such) responded to our survey.*

Sampling Criteria

A number of criteria were used to select the sample. First, it was decided to sample institutional types (nursing homes, hospitals) in proportion to their frequency rather than in relation to the number of persons residing in them.**

Sponsorship - Sponsorship of nursing homes varies markedly from sponsorship of hospitals. Nursing homes tend to be run as private businesses, hospitals tend to be operated by communities or non-profit agencies. Therefore, each institutional type was surveyed in relation to individual patterns of sponsorship.

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*It may be that these institutions were misclassified on the MFI survey or have changed their focus since the survey: in other instances, a portion of the overall institution may be designated for these types of services. Finally, some states simply license such facilities as nursing homes and they end up being counted as such.

**The latter method might have been preferred had the basic unit of analysis been the individual rather than the institution. The ratio of the number of hospitals to nursing homes has remained fairly constant over the past five years at 3 to 7. Of the 4,000 facilities sampled, 3,080 were nursing homes and 920 were hospitals. Other approaches were considered as those reviewed in: Hess, Riedel, and Fitzpatrick (1975).

For the 3,080 nursing homes, 70 percent (2,156) were selected from private/for-profit facilities, 10 percent (308) from government operated institutions, and 20 percent (616) from among non-profit/church related facilities. For the 920 hospitals, this pattern was reversed. Ten percent (92) were proprietary hospitals, 49 percent (368) were government instutions, and 50 percent (460) were non-profit facilities.*

Size - An effort was made to reflect the full range of small, medium and large facilities designated as follows:**

Small facilities = institutions which have a bed count of less than or equal to 1/2 the mean bed count for that state;

Medium facilities= institutions which have a bed count of between greater than 1/2 the mean bed count and less than twice the mean bed count for that state;

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*Sources of data used to compute sponsorship and size were: American Nursing Home Association, (1971); American Hospital Association, (1977).

**Most research has over-sampled from the larger homes, not reflecting a national average for nursing homes of under 90 beds, and a national average for hospitals of 205 beds.

Large facilities = institutions which have a bed count of at least twice the mean bed count for that state.

Institutions were surveyed at the rate of 25 percent of small facilities, 50 percent of medium, and 25 percent of large.

Geographic Drawing Area - An effort was made to select facilities geographically distributed across each state. For example, if several facilities met the criteria, those of different zip codes were selected.

Sampling Procedure - A systematic random sample of nursing homes and hospitals was drawn by selecting one in eight facilities, stratified by state.* If under-representation occurred for a given category (i.e., small/government facility), after going through the list once, the required additions were selected from the remaining facilities by going through the list again, and selecting every eighth facility. This is summarized in Tables 4-1 and 4-2.

Pretest - Institutions selected for the pretest were also picked using the same general criteria. For the pretest, two hospitals and two nursing homes were selected for each state.

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*In some states the strata were so small that certain types of facilities were not sampled. Consistent with the non-institutional survey, this did not pose any problem since only regional or national analyses were planned. The sampling was organized by state primarily for reason of convenient access to sampling frames listed in this manner, and to facilitate mailing.

Table 4-1

Frequency of Each Type of Institution Selected:
Hospital Sample Institutional Mail Survey

Region and State	Total Hopsitals in State	Total to be Sampled	Average Size of Hospitals in State	Proprietary			Governmental			Non-Profit			TOTAL
				Small	Medium	Large	Small	Medium	Large	Small	Medium	Large	
I CONNECTICUT	69	19	297	0	0	0	1	2	1	1	2	1	8
MAINE	55	17	98	0	0	0	1	1	1	1	2	1	7
MASSACHUSETTS	195	25	216	1	1	1	3	5	3	3	6	3	26
NEW HAMPSHIRE	34	4	123	0	0	0	0	1	0	1	1	1	4
RHODE ISLAND	22	3	249	0	0	0	0	1	0	0	1	0	2
VERMONT	21	3	269	0	0	0	0	1	0	0	1	0	2
II NEW JERSEY	146	19	280	0	1	0	2	4	2	2	5	2	18
NEW YORK	407	53	256	1	3	1	5	11	5	7	13	7	53
PENNSYLVANIA	320	41	229	1	2	1	4	8	4	5	10	5	40
III DISTRICT OF COLUMBIA	20	3	381	0	0	0	0	1	0	0	1	0	2
DELAWARE	15	2	250	0	0	0	0	0	0	0	1	0	1
FLORIDA	239	31	190	1	2	1	3	6	3	4	8	4	32
GEORGIA	182	24	131	1	1	1	2	5	2	3	6	2	24
MARYLAND	82	11	271	0	1	0	1	2	1	1	3	1	10
NORTH CAROLINA	161	21	162	0	1	0	2	4	2	3	5	3	20
SOUTH CAROLINA	88	11	150	0	1	0	1	2	1	1	3	1	10
VIRGINIA	129	17	194	0	1	0	2	3	2	2	4	2	16
WEST VIRGINIA	86	11	145	0	1	0	1	2	1	1	3	1	10
IV ALABAMA	147	19	132	0	1	0	2	4	2	2	5	2	18
KENTUCKY	127	16	136	0	1	0	2	3	2	2	4	2	16
MISSISSIPPI	115	15	102	0	1	0	2	3	2	2	4	2	16
TENNESSEE	158	20	155	1	1	1	2	4	2	3	5	2	22
V ARKANSAS	96	12	102	0	1	0	1	2	1	2	3	2	12
LOUISIANA	156	20	124	1	1	1	2	4	2	3	5	3	22
OKLAHOMA	147	19	96	0	1	0	2	4	2	2	5	2	18
TEXAS	571	74	110	2	4	2	7	15	7	9	19	9	74

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Table 4-1 (continued)

Region and State		Total Hopsitals in State	Total to be Sampled	Average Size of Hospitals in State	Proprietary			Governmental			Non-Profit			TOTAL
					Small	Medium	Large	Small	Medium	Large	Small	Medium	Large	
VI	ILLINOIS	289	37	221	1	2	1	4	7	4	5	9	5	38
	INDIANA	138	18	207	0	1	0	2	4	2	2	5	2	18
	MICHIGAN	254	33	186	1	2	1	3	7	3	4	8	4	33
	OHIO	251	33	234	1	2	1	3	7	3	4	8	4	33
	WISCONSIN	176	23	160	1	1	1	2	5	2	3	6	3	24
VII	IOWA	144	19	127	0	1	0	2	4	2	2	5	2	18
	KANSAS	166	22	87	1	1	1	2	4	2	3	6	3	23
	MINNESOTA	192	25	137	1	1	1	3	5	3	3	6	3	26
	MISSOURI	171	22	172	1	1	1	2	4	2	3	6	3	23
	NEBRASKA	109	14	95	0	1	0	1	3	1	2	4	2	14
	NORTH DAKOTA	60	8	81	0	0	0	1	2	1	1	2	1	8
	SOUTH DAKOTA	79	9	64	0	0	0	1	2	1	1	2	1	8
VIII	ARIZONA	78	10	144	0	1	0	1	2	1	1	3	1	10
	COLORADO	101	13	130	0	1	0	1	3	1	2	3	2	13
	IDAHO	52	7	67	0	0	0	1	1	1	1	2	1	7
	MONTANA	65	8	65	0	0	0	1	2	1	1	2	1	8
	NEVADA	23	3	135	0	0	0	0	1	0	0	1	0	2
	NEW MEXICO	54	7	98	0	0	0	1	1	1	1	2	1	7
	UTAH	39	5	109	0	0	0	1	1	1	1	1	1	6
	WYOMING	30	4	64	0	0	0	0	1	0	1	1	1	4
IX	CALIFORNIA	638	83	152	2	4	2	8	17	8	10	21	10	82
	OREGON	87	11	114	0	1	0	1	2	1	1	3	1	10
	WASHINGTON	127	16	111	0	1	0	2	3	2	2	4	2	16
	TOTAL sample by size and sponsorship	7111	940	7808	18	47	18	91	186	91	114	235	114	914
	TOTAL hospital sample by sponsorship		15,859			83			368			463		914

Table 4-2

Frequency of Each Type of Institution Selected:
Nursing Home Sample Institutional Mail Survey

Region & State	Total Nursing Homes	Total To be Sampled	Average Size of Nursing Homes in States	Proprietary 1 Small	Proprietary 2 Medium	Proprietary 1 Large	Governmental 3 Small	Governmental 4 Medium	Governmental 3 Large	Non-Profit Small	Non-Profit Medium	Non-Profit 4 Large	TOTAL
I CONNECTICUT	401	51	46	9	18	9	1	3	1	3	5	3	52
MAINE	390	50	19	9	18	9	1	3	1	3	5	3	52
MASSACHUSETTS	1015	130	43	23	46	23	3	7	3	7	13	7	132
NEW HAMPSHIRE	147	19	36	3	7	3	0	1	0	1	2	1	18
RHODE ISLAND	167	21	30	4	7	4	0	1	0	1	2	1	20
VERMONT	112	14	26	2	5	2	0	1	0	1	1	1	13
II NEW JERSEY	581	75	49	13	26	13	2	4	2	4	8	4	76
NEW YORK	1201	154	76	27	54	27	4	8	4	8	15	8	155
PENNSYLVANIA	862	111	80	19	39	19	3	6	3	6	11	6	112
III DISTRICT OF COLUMBIA	88	11	32	2	4	2	0	1	0	1	1	1	12
DELAWARE	50	6	57	1	2	1	0	0	0	0	1	0	5
FLORIDA	407	52	105	9	18	9	1	3	1	3	5	3	52
GEORGIA	328	42	73	7	15	7	1	2	1	2	4	2	41
MARYLAND	229	29	68	5	10	5	1	1	1	1	3	1	28
NORTH CAROLINA	866	111	21	19	39	19	3	6	3	6	11	6	112
SOUTH CAROLINA	131	17	46	3	6	3	0	1	0	1	2	1	17
VIRGINIA	372	48	40	8	17	8	1	2	1	2	5	2	46
WEST VIRGINIA	146	19	24	3	7	3	0	1	0	1	2	1	18
IV ALABAMA	210	27	66	5	9	5	1	1	1	1	3	1	27
KENTUCKY	323	41	51	7	14	7	1	2	1	2	4	2	40
MISSISSIPPI	148	19	52	3	7	3	0	1	0	1	2	1	18
TENNESSEE	236	30	45	5	11	5	1	2	1	2	3	2	32
V ARKANSAS	235	30	67	5	11	5	1	2	1	2	3	2	32
LOUISIANA	233	30	64	5	11	5	1	2	1	2	3	2	32
OKLAHOMA	424	54	61	9	19	9	1	3	1	3	5	3	53
TEXAS	1031	132	65	23	46	23	3	7	3	7	13	7	132

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Table 4-2 (continued)

Region & State		Total Nursing Homes	Total To be Sampled	Average Size of Nursing Homes in States	Proprietary 1 Small	Proprietary 2 Medium	Proprietary 3 Large	Governmental 1 Small	Governmental 2 Medium	Governmental 3 Large	Non-Profit 1 Small	Non-Profit 2 Medium	Non-Profit 3 Large	TOTAL
VI	ILLINOIS	1121	144	57	25	50	25	4	7	4	7	14	7	143
	INDIANA	526	67	51	12	23	12	2	3	2	3	7	3	67
	MICHIGAN	656	84	69	15	29	15	2	4	2	4	8	4	83
	OHIO	1287	165	43	29	58	29	4	8	4	8	17	8	165
	WISCONSISN	597	77	79	13	27	13	2	4	2	4	8	4	77
VII	IOWA	701	90	41	16	32	16	2	5	2	5	9	5	92
	KANSAS	487	62	41	11	22	11	2	3	2	3	6	3	63
	MINNESOTA	645	83	58	15	29	15	2	4	2	4	8	4	83
	MISSOURI	537	69	58	12	24	12	2	3	2	3	7	3	68
	NEBRASKA	268	34	52	6	12	6	1	2	1	2	3	2	35
	NORTH DAKOTA	114	15	53	3	5	3	0	1	0	1	2	1	16
	SOUTH DAKOTA	166	21	42	4	7	4	0	1	0	1	2	1	20
VIII	ARIZONA	110	14	60	2	5	2	0	1	0	1	1	1	13
	COLORADO	276	35	61	6	12	6	1	2	1	2	4	2	36
	IDAHO	71	9	62	2	3	2	0	0	0	0	1	0	8
	MONTANA	112	14	43	2	5	2	0	1	0	1	1	1	13
	NEVADA	41	5	24	1	2	1	0	0	0	0	1	0	5
	NEW MEXICO	80	10	43	2	4	2	0	1	0	1	1	1	12
	UTAH	161	17	34	3	6	3	0	1	0	1	2	1	17
	WYOMING	39	5	47	1	2	1	0	0	0	0	1	0	5
IX	CALIFORNIA	4897	628	27	110	220	110	16	31	16	31	63	31	628
	OREGON	329	42	51	7	15	7	1	2	1	2	4	2	41
	WASHINGTON	452	58	61	10	20	10	1	3	1	3	6	3	57
	TOTAL sample by size and sponsorship	24,006	3071	2499	535	1078	535	72	158	72	158	308	158	3074
	TOTAL sample by sponsorship		29,576			2148			302			624		3074

Response Rates in Mail Survey

An overall response rate of 42% was achieved with 1660 usable surveys from the initial sampling frame of 4,000 facilities. (See Tables 4-3 and 4-4.) Hospitals responded at a slightly higher rate (49%) as compared to nursing homes (39%): 88% of the non-usable returned responses were from nursing homes. Both of these findings suggest that hospitals are more accustomed to filling out surveys and have the staff and records to do so easily.

Responses to institutional surveys are typically poor, as Brody (1977) reports, due to institutionalized staff being overburdened by paper work and governmental queries that detract from providing patient care. Our response rates are thought fairly successful. Based on rank correlations, relative response rates by hospitals and nursing homes within states were fairly consistent.

Three separate mailings of the questionnaire were made. The first mailing was made at the beginning of February 1977. The response rate on this initial mailing directed to the institutions' Executive Director or Administrator was only 19%. For the second mailing, (posted about four weeks after the first mailing), the cover letter was strengthened and personalized. The survey was then sent to the Director of Activities or Director of Nursing. The response rate increased then to 26%. A third mailing in a different color paper stock was sent about four weeks after the second mailing. The cover letter was again changed and sent to the Director of Activities or Nursing.

Table 4-3

Total Institutional Survey Sample: Response Rate By Questionnaire Mailing

SURVEY INFORMATION	HOSPITALS Number	HOSPITALS Percent	NURSING HOMES Number	NURSING HOMES Percent	TOTAL Number	TOTAL Percent
1. Total Mailed	914	23	3,074	77	3,998	100
2. Total Returns	473	23	1,606	77	2,079	100
a. Gross percent returned ÷ Total Mailed	473/914	52	--	52	--	52
b. Usable surveys received	449	27	1,211	73	1,660	100
c. Incomplete/Nonusable rec'd	4	12	28	88	32	100
d. Post Office Returns	12	3	335	97	347	100
e. Other: Uncodable	8	25	32	75	40	100
f. Total Non-usable surveys rec'd	24	6	395	94	419	100
3. Net Usable Surveys ÷ Total Mailed		49		39		42
4. Net Usable Surveys ÷ Total U.S. Institutions	449/7,102	6.3	1,121/24,007	4.7	1,660/31,109	5.3
5. Response Rate Based on Total Usable Surveys ÷ (Total Mailed - P.O. Returns)	449/902	50	1,211/2,739	44	1,660/3,641	46

Table 4-4

Impact of Sequential Mailings for Institutional Survey Return and Response Rate*

MAILING	HOSPITALS Number	HOSPITALS Percent	NURSING HOMES Number	NURSING HOMES Percent	TOTAL Number	TOTAL Percent
Total Mailed	914	23	3,074	77	3,988	100
Rec'd Usable	449	27	1,211	73	1,660	100
1st Mailing	67	15	246	20	313	19
2nd Mailing	205	46	518	43	723	44
3rd Mailing	115	26	291	24	406	24
Phone Backs	62	14	156	13	218	13

*Phone calls were made to a subsample of 500 non-respondents; not to the entire non-respondent sample. The subsample was randomly drawn. Thus of 500 possible, the subsample yielded an overall response rate of 43.6% (218/500).

Dates of mailings were: 1st- February 9, 1978; 2nd- March 17, 1978; 3rd, April 19, 1978; Telephone follow-up commenced April 25, 1978 and ran for two weeks and two days.

The response rate then increased to 38%. In an effort to increase the response rate further, personal telephone calls were made at the time of the third mailing to some 500 institutions. The response rate of institutions called was 44%.

To simplify return mailing of the four-page survey for respondents, the surveys were self-addressed by AFB with prepaid postage. No envelope was required: the respondent merely had to fasten a tab and post. Consequently, the reason that response rate was not higher is probably due to a lack of interest on the part of institutions and their occupation with other responsibilities.

Throughout the mailings, delays in the postal service were major problems. From examination of franking dates, it was suspected that the postal service may have treated the first mailing of the surveys, sent in brown manilla envelopes, as third class mail. Examination of the franking dates and dates of completion listed by respondents gave us concern for the speed with which responses were being delivered after posting. For the subsequent mailings, white envelopes imprinted with the words "first class mail" were used. Despite a double checking of addresses, the large number of surveys returned as undeliverable also troubled us. These returns have not been analyzed by size, sponsorship or location, but 97% of them were nursing homes, possibly reflecting that a large number had gone out of business.

Processing the Mail Questionnaires

Selecting Usable Response - Three basic items were necessary to judge the survey as usable. First, questionnaires where more than ten percent of the questions were answered, were included. Many of the 32 questionnaires returned incomplete were accompanied by a letter indicating there were no persons with reading disabilities in the institution, the staff did not have time to complete the survey, or the survey recipients felt that the NLS/BPH program was inappropriate to their particular type of institution ("our people are very old," "we are a hospital." This suggested that they would use the program if they did admit an eligible individual--typically referred to as a "blind person").

Second, duplicated surveys were omitted. Due to multiple mailings, it was possible for an institution to mail out one copy rather tardily and, meanwhile, receive a second. Eight institutions filled out more than one survey, typically by a different person. As might be expected, there were differences between responses given in the two returned copies; usually there was agreement on basic questions, such as whether the institution had current users of Talking Books, but variations were common (about fifty percent of the time) on questions regarding problems, goals, and characteristics of the institutional population. In cases of multiple response, the most complete

questionnaire was selected for inclusion.

Third, due to time requirements of the study, an arbitrary cut-off date for inclusion was set, eight weeks after mailing the last round of questionnaires. Fewer than ten were received after this deadline.

Editing and Coding - A coding manual was developed in two parts: the first was a straight forward translation of the closed-ended questions, and the second was a system for assigning categories to the numerical data and open-ended responses. To develop the coding system for grouping numerical and open-ended responses, a subsample of 200 questionnaires were randomly selected. This subsample was carefully reviewed, categories were developed for the open-ended questions, and difficult coding problems were identified.*

Coders were recruited and trained to assign state codes, check that respondents had selected the appropriate number of responses for the individual items, check consistency on numerical questions, and code open-ended data. Codes for sponsorship (voluntary, private, and public sponsorship) were taken from the Master Facility Inventory files and matched with appropriate institutions.

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* One particularly unsettling problem, which could not be resolved clearly, was the lack of distinction made by respondents between possession and use of NLS/BPH equipment.

The first 100 surveys completed by each of the coders were reviewed twice: once by another coder, and once by a supervisor. Coders set aside any surveys requiring judgments not included in their codebooks; judgments were then made by supervisors and decisions entered into the coding manual in a systematic manner. All surveys were reviewed by a second coder and spot checked by project staff. Coding required 63 person days of clerical staff time and 16 person days of supervisory time.

Data cleaning and analysis were accomplished by AFB staff with the computer processing subcontractors.

SITE VISITS

Selection of States for Institutional Site Visits

In attempting to maximize geographical coverage while still remaining within budget constraints, seven states were selected for site visits to health care facilities. The choice of the seven states was based on the following criteria:

1. A Range of Utilization of Braille and Recorded Books and Magazines.

An analysis of the relative utilization of the NLS/BPH program for 1975, the latest year of data availability,* was made by calculating the ratios of the number of nursing homes using the program in each state to the number of nursing homes and the number of hospitals in each state using the program to the hospitals. This is shown in Figure 4-1. Listings were then made of states which had very high or very low use patterns in nursing homes and/or hospitals, or great disparity of use.

2. Geographical Distribution

Since national coverage was required, efforts were made to select states with a range of population densities. No two adjacent states were to be visited.

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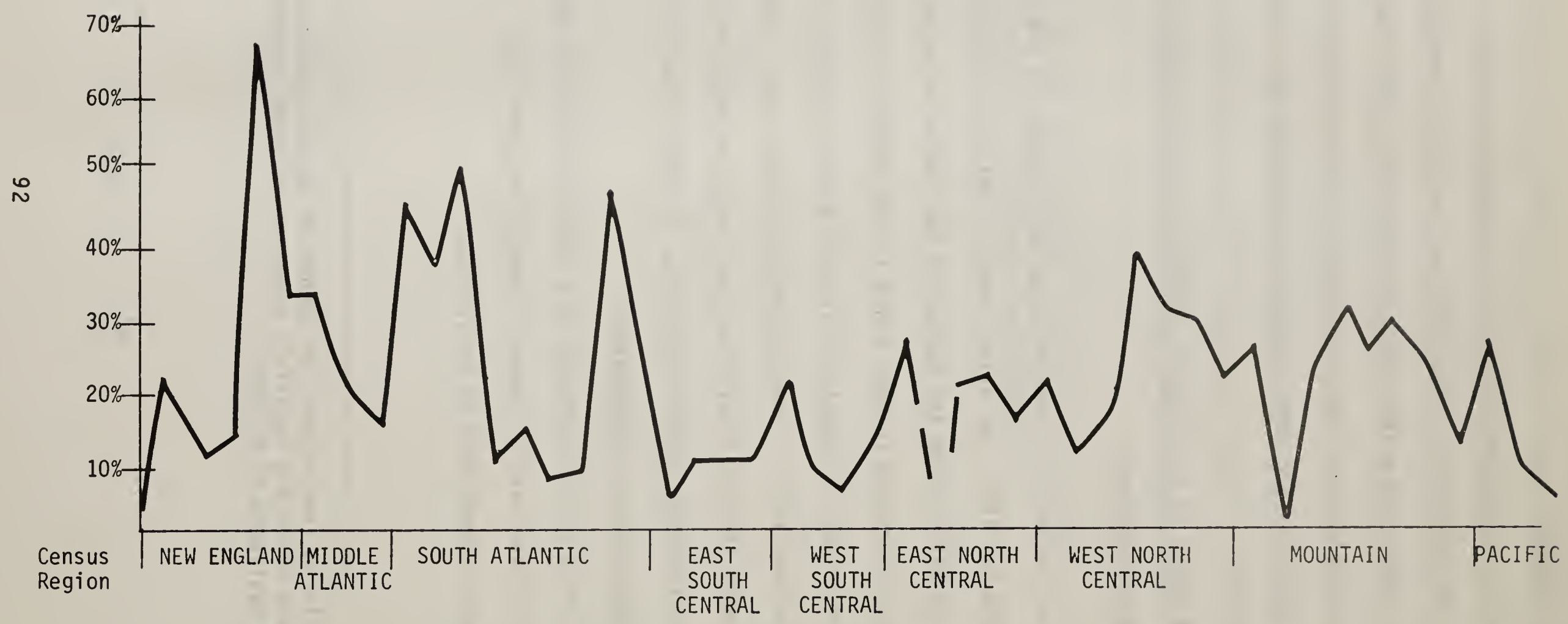
*Calculated from reports of number of deposit collections in nursing homes and hospitals prepared by state regional libraries made available by NLS/BPH.

Figure 4-1

Average Institutional Utilization of NLS/BPH Deposit Collections in Nursing Homes and Hospitals (Hospital Utilization + Nursing Home Utilization ÷ 2) by State Within Census Region--1975



Source: NLS/BPH statistics on institutional deposit collections in nursing homes and hospitals, divided by the number of nursing homes and hospitals in each state, and then averaged.

3. Other Factors

States were excluded on the following basis:

a: Alaska, Hawaii and the United States territories, which were omitted in the other parts of the AFB study.

b: States that were previously studied by NLS/BPH.

c: States with no regional NLS/BPH library.

The final selection included one state from the following census regions: New England, West South Central, East North Central, West North Central, Mountain, Pacific, and South Atlantic.

Site Selection, Institutional Sample

Our contract called for 35 site visits, but this was expanded to a minimum of six institutions per state in order to get a balance of institutional types (see Table 4-5). These facilities were selected as a representative subsample of the institutions drawn for the mail survey.

Table 4-5

Sampling by Facility Type

Type of Facility	Percent to be Selected
Hospitals	10
Health Care Residences	70
Skilled Nursing (30%)	
Intermediate Care (30%)	
Board & Care (10%)	
Apartments for Handicapped	2
Apartments for Elderly	2
Schools and Centers for the Blind	6

Institutional size, sponsorship, and community size were three additional selection criteria.

Size - Less than 40 beds, 40-120 beds, and over 120 beds were set as the parameters for small, medium and large health care residences, respectively. For hospitals, which tend to be larger, parameters were altered to small (less than 100 beds), medium (100-300 beds), and large (over 300 beds).

Sponsorship - Taken as a whole, facilities were selected so that for each state approximately three or four (1/2 or 2/3) would be private, for-profit health care residences. Due to the small proportion of private hospitals, none were visited. Since homes for the aged tend to be heavily church- and governmentally-sponsored rather than private, some weighting was done in favor of the non-profit/governmental facilities of this type. As most schools for the blind and physically handicapped persons are governmentally sponsored, no effort was made to include examples from other sponsorship types.

Statewide and Community Size Distribution - Subject to the condition of selecting sites no more than a half day's travel apart, facilities were selected from different parts of each state from urban and suburban/rural settings.

In the process of selection, the first step involved preparing listings of hospitals and nursing homes from the MFI and AHA files by state, facility type, sponsorship and size. For each state, the first facility selected was a hospital, school for the

blind, and/or apartment unit because these types of facilities were scarce. The proposed hospital sites were next color coded and plotted on a road map, and keyed according to size and sponsorship. After all the possibilities were mapped, exclusions were made so that the resulting facilities would represent a range of sponsorship types, size and community populations.

Homes for the Aged and hospitals were plotted in a similar fashion. Exclusions were made in three states due to the small number of choices.

For each state the goal was to include at least one instance of either skilled or intermediate care facility in each size group, (large, medium, small) and for each sponsorship type (private, voluntary, government). In model states, both skilled and intermediate care nursing homes were visited in about equal proportions.

Adjustments were again made for geographic distribution and community size. If several communities were judged similar in type (rural, industrial, mountain, urban, etc.), they were grouped and a selection was made to limit duplication. Facilities were excluded that were in apparent states of flux, as indicated by a very low occupancy rate (indicating either closing down, imminent new construction, or sometimes, management problems). In each state, one or two facilities had to be added later to achieve fuller geographic distribution, and to serve as back-ups.

Process of Scheduling

Telephone calls were made to each institution selected. (See Appendix for script.) The first contacts were made to: a) explain the purpose of the visit, b) request participation or an opportunity to visit, c) indicate any adaptations to standard interview procedures that might be required due to the size or complexity of the institution,and d) establish a tentative date and time. Travel logistics determined tentative dates for visits. Each administrator or contact person was called again to set the specific time and date; confirmation letters were then prepared and mailed. The interviews were performed during the period November 1977 through June 1978.

Response Rates - Perhaps owing to the inherent interest in improving services,of the 54 institutions contacted, 50 agreed to participate. The four refusals were due to: the facility did not want a person from a government-related agency on the premises, dates available conflicted with board visits or health department inspection, not interested.* Interviews were conducted at 47 sites. Three visits had to be cancelled by researchers because of inability to make travel arrangements during a snow storm and illness of AFB staff.

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* Three of the refusals were from one eastern state.

Conducting the Interviews - On Site Work

A relatively uniform procedure was followed at each institution in order to maximize compatibility of the data and make the most of limited time. Briefly, each visit was preceded by a confirmation of the planned visit on the prior day; analysis and recordings were made of a description of site location and neighborhoods along with facility design, construction and layout; and a directed but casual questioning was conducted of community residents, neighbors and facility staff regarding community and neighborhood characteristics, history and life styles. An interview was then conducted with the Administrator followed by a tour of the facility and interviews with the Activity Director, In-Service Director, Librarian, Occupational Therapist, other staff, and residents.

During the interviews and observations, notes were made on such factors as lighting, acoustics, patterns and use of space, work activity, availability of reading space and materials, type of sleeping accomodations and examination areas. Usually the Administrator was again interviewed just prior to leaving, expressing appreciation, indicating highlights of the visit, and arranging to get any additional data. Most visits lasted about five hours--with variations of 1 to 12 hours for the smallest to the most complex facilities. Directly following the visits, a guided format for debriefing was used to organize notes and observations.

Interview Technique for Site Visits - A number of observations of a personal nature related to interview technique that might aid other researchers were made. Travel from a substantial distance impressed many institutional staff. The fact that the Library of Congress "really cares" translated into grass-roots involvement and appeared to enhance our ability to obtain appointments and frank responses. Conversely, the research staff needed to be prepared to respond to specific questions for assistance or to refer questions to local resources (libraries or health care centers). The ability to objectively conduct an interview without becoming personally involved in the opinions expressed was essential to eliciting cooperation. Being conversant with all aspects of health care facilities and national issues such as paperwork, licensure, regulatory variations, etc., facilitated conversation and the procurement of relevant data. It was also beneficial that the AFB project staff had travelled extensively and were comfortable in small, poor and rural communities as well large, wealthy and urban ones -- but care was taken to protect anonymity of other institutions visited and to respond only generally to questions of where and what was seen. In completing the site visits, it was important to set aside first impressions of the institution and its sophistication or other "surface phenomena."

The project team found it successful to take the view point of a student of each particular institution and program, rather than that of an evaluator. The interview technique that was most effective with institutional staff and administrators alike involved asking, "How does _____happen?" "What is your experience with ____?" "Some people find _____, has that been your experience?" "I notice this_____." "Is that an outsider's impression or are people really _____?" "Would you help me understand _____or how you deal with_____?" Taking the approach of ethnographers, our assumption was that some form of logic in the institution was operating, and it was important to understand the institution's perspective. Similarly, no matter how the researcher might personally feel about the perceived social experience of a community, the institutional life, rules, or procedures, it was important to communicate curiosity and empathize or react with understanding to the speaker's response, i.e. supportive interviewing.

In our interviews with patients or residents, it was necessary to stress the research objective rather than direct service nature of the visit. It was distressing for the AFB project staff to see residents with needs that could be met, yet were not. During debriefings with institutional staff, the project team was alert to pass on residents' questions such as, "I want a Talking Book machine but was told I had to be blind."

So that discussions could be conducted informally, it was found useful to memorize the interview instruments. Responses were written throughout. At the close of each session, the interview forms were reviewed and any topics not previously covered were discussed. Although this led to extensive debriefing by the project staff directly following the interviews, the procedure reduced formality and tension. It is estimated that for each hour of interviewing, two hours were spent in debriefing. Tape recordings were not made, although some photographic documentation with permission was made of the facilities and residents.

Post offices, restaurants, drug stores, and hotel clubs were excellent sources of basic community facts. In most cases this background information was obtained prior to visiting the site, and greatly facilitated initial staff and resident discussions. Examples include history of the city, major industries, economic indicators, growth, other health facilities, features of the community, and availability of jobs in health fields. Yellow page ads were checked for information on institutions. Maps and postcards were also gathered to fill out local "color."

Analysis of Site Visit Data

The site visit data were compiled from debriefing notes that had been systematically prepared after each visit. These included

discussions on factors affecting use and non-use as perceived by staff, residents and interviewers. These were subsequently content analyzed, and examples and themes were abstracted for use in the final report. Due to the small sample size, the site visit questionnaire data were then tabulated by hand.

Limitations of the Site Visits

The major limitation of the sample was its size.

The overall number of states and institutions visited was small: hence, the ability to make generalizations from the data is limited. A check on reliability of responses was achieved when two AFB staff members visited a facility, which occurred for about half of the sites. During debriefings, information was reviewed and impressions of the facility and its program were fully discussed.

There were many instances where the data obtained from mail surveys conflicted with site visit interview data and experiences. This may indicate that the staff filling out the survey did not always have a full perspective of the institution, or treated the mail survey somewhat superficially.

METHODOLOGY AND SAMPLE DESCRIPTION FOR THE SURVEY OF REGIONAL LIBRARIANS

It is difficult for any sample of a small population to be representative of that population. From a population of 56 regional librarians, situated in 48 states plus Washington, D.C., the National Library Service suggested 12 states to reflect the national picture. Four additional states were selected to match the location of site visits made in the Institutional Sub-Study. The resulting sample of Directors of regional libraries in 16 states equalled approximately one third of all regional library chiefs.

Six major topic areas were examined in structured telephone interviews lasting about two and a half hours each. These were: current and future plans; programs provided; library administration; relationship to NLS/BPH; reader profiles, and issues of service delivery. Each of these topic areas is presented in the guided interview forms found in the Appendix.

The characteristics of the sample are presented in Table 5-1.

Table 5-1

Profile of the Regional Libraries Surveyed

Characteristics	Percent
1. REGIONAL DISTRIBUTION:	
Northeast	31
South	31
Midwest/North Central	25
West	13
2. AFFILIATION:	
State Library	69
Local Public Library (city or county)	6
Combination State/Local Public Library	13
Other State Agency	6
Private/Non-profit Organization	6
3. FACILITY LOCATION:	
Shared Facilities:	
With State Library*	38
With Public Library	25
With Other Agency	13
Free Standing Facility(ies)	25
4. AGE:	
Pre-1931 Origin	31
1931-1949	13
1950-1969	31
1970-Present	25
5. GEOGRAPHIC RESPONSIBILITY:	
Multi-State + Own State	6
More Than 1 State/Several Services	6
More Than 1 State/Braille	6
State Boundaries**	62
Area/Section Within A State	19
6. SERVICE ORIENTATION:	
Central Service/No Subregionals	50
States With Subregionals	50

Percents may not add to 100 due to rounding.

*Two of these have just moved or are moving to the state.
**State boundaries were listed for two that had subregional libraries.

Appendix A

Screening Questionnaire

TRENDEX, INC. 15 RIVERSIDE AVENUE WESTPORT, CT. BLIND AND HANDICAPPED QUESTIONNAIRE JANUARY, 1977 BUYERSHIP WAVE 76-4 - PART I - #01701 /B/

INTERVIEWER INITIALS_____ INTERVIEWER #__ __ __ __ __ CITY CODE #__ __ - __ __ __ __ __ CITY & STATE_____
5 6 7 8 9 10 11

RESPONDENT'S PHONE #_____ RESPONDENT'S NAME_____ RESP. ADDRESS_____
(area code) Street & Number City/Town State

ASK EVERYONE

Next, I'd like to ask you some questions that are really quite different from the ones I've asked before. They have to do with certain free public library services. After I read you the questions, please answer "Yes" or "No" if any one of the three questions applies to your household.

(If respondent says Yes to any one or more, circle "Yes".)

A. Are there any members of your household, including yourself, who are unable or find it difficult to read regular print even with eye glasses?
B. Are there any persons who are unable or find it difficult to hold or turn the pages of a book or magazine?
C. Are there any persons having reading difficulties because of any other physical problems?

Yes 76-1
No -2

NOTE TO INTERVIEWER: Record answers to Questions 1A/1B through 8 in grid below.

YOU MENTIONED EARLIER THAT SOMEONE IN YOUR HOUSEHOLD HAS DIFFICULTY READING BECAUSE OF A VISUAL OR PHYSICAL PROBLEM.

1. DO YOU, YOURSELF, HAVE THIS PROBLEM? (Ask Q.1A) ← Yes 17 -1
(Skip to Q.1B) ← No -2

1A. WHAT IS YOUR NAME? (Record below and skip to Q.2)

1B. WHAT IS THE NAME OF THE PERSON WITH THIS PROBLEM?

2. Record sex. If other than respondent, ask: IS THIS PERSON A MALE OR FEMALE?

3. HOW OLD IS HE/SHE (ARE YOU)?

4. (If person with the visual or physical problem is other than respondent, ask Q.4. Otherwise, skip to Q.5) WHAT IS YOUR RELATIONSHIP TO HIM/HER?

5. WHAT IS THE NATURE OF HIS/HER/YOUR PROBLEM?

6. IS THIS A PERMANENT PROBLEM?

7. (If the person with the visual or physical handicap is other than respondent, ask Q.7. Otherwise, skip to Q.8.) IF WE WERE TO CALL BACK AT A LATER DATE TO DISCUSS FREE LIBRARY FACILITIES, WOULD IT BE POSSIBLE TO TALK DIRECTLY WITH (person named in Q.1B)?

8. IS THERE ANYONE ELSE IN YOUR HOUSEHOLD WHO HAS DIFFICULTY READING BECAUSE OF A VISUAL OR PHYSICAL PROBLEM? (If Yes, repeat questions 1B through 8 until all persons with a visual or physical problem have been covered (up to 3 persons). If No, thank and terminate.)

1st Person			2nd Person			3rd Person		
Q.1A/B--Name:_____			Q.1A/B--Name:_____			Q.1A/B--Name:_____		
Q.2--Sex:	Male	18 -1	Q.2--Sex:	Male	26 -1	Q.2--Sex:	Male	34 -1
	Female	-2		Female	-2		Female	-2
Q.3--Age:	_____	19 -	Q.3--Age:	_____	27 -	Q.3--Age:	_____	35 -
Q.4--Resp.'s relationship	_____	20 -	Q.4--Resp.'s relationship	_____	28 -	Q.4--Resp.'s relationship	_____	36 -
Q.5--Nature of problem:	_____		Q.5--Nature of problem:	_____		Q.5--Nature of problem:	_____	
	_____			_____			_____	
	_____			_____			_____	
	_____			_____			_____	
	_____	21 -		_____	29 -		_____	37 -
	_____	22 -		_____	30 -		_____	38 -
Q.6--Permanent problem?	Yes	23 -1	Q.6--Permanent problem?	Yes	31 -1	Q.6--Permanent problem?	Yes	39 -1
	No	-2		No	-2		No	-2
Q.7--Talk directly?	Yes	24 -1	Q.7--Talk directly?	Yes	32 -1	Q.7--Talk directly?	Yes	40 -1
	No	-2		No	-2		No	-2
Q.8--Anyone else?	Yes	25 -1	Q.8--Anyone else?	Yes	33 -1			
	No	-2		No	-2			

05

Appendix B

Call-Back Questionnaire

TRENDEX, INC. 15 RIVERSIDE AVENUE WESTPORT, CT.

BLIND AND HANDICAPPED CALLBACK - JOB #03707/B/ Case ID#___ ___ ___ ___ ___ ___
1 2 3 4 5 6

(Fill in name of desired respondent from screening questionnaire--see notes below)

NAME _____

ADDRESS: _____
Street and number City or Town State Zip Code

RESPONDENT'S PHONE #(____) _____
area code

BUYERSHIP CITY CODE #___ ___-___ ___ ___ ___ ___
7 8 9 10 11 12 13

STATE CODE: _____ _____
14 15

REGION CODE: _____ 16 -

METRO/NON-METRO _____ 17 -

(FOR OFFICE USE ONLY)

INTERVIEWER INITIALS _____ INTERVIEWER #___ ___ ___ ___ ___
18 19 20 21 22

(Write in location of nearest Regional or Sub-Regional library (see enclosed list)

_____

RECORD OF CALLS TO RESPONDENT:

Date	Time	Results
_____	_____	_____
_____	_____	_____
_____	_____	_____

Time Started: _____

NOTES TO INTERVIEWER:

1. If more than one person in a household has a reading problem, conduct the interview with the first person designated on the screening questionnaire.
2. Ask to speak with the first handicapped person designated in Q.1A/B on the screening questionnaire unless person is unable to use the telephone ("No" to Q.7 on screening questionnaire), or unless handicapped person is under 16 years of age (see Note #4 below).
3. If desired person is unavailable, arrange an appointment to call back. If, on calling back twice, the handicapped person is still unavailable, ask to speak with a person 16 years of age or older who knows the desired respondent well, and correct the wording of the introduction and questions appropriately (i.e. instead of "you", substitute "he" or "she".)
4. Conduct a proxy interview:
   a. if the handicapped person is unable to use the telephone ("No" to Q.7 on screening quest.) or
   b. if the handicapped person is under 16 years of age.

   Ask to speak with a person 16 years of age or older who knows the desired respondent well--for example, the person named at the top of the screening questionnaire after "Respondent's Name", and correct the wording as in Point #3 above.
5. If proxy respondent is unavailable, arrange a callback. Make every effort to complete the interview.
6. If totally unable to conduct interview for 1st person designated on screening questionnaire, follow same procedure above for 2nd person designated, or 3rd person if 2nd is unavailable. Complete one interview per household.

- -

HELLO. MAY I PLEASE SPEAK WITH (name of desired respondent)? (When desired respondent is on the phone, continue): THIS IS (your name) OF TRENDEX RESEARCH. I HOPE YOU RECEIVED OUR LETTER SAYING WE WOULD CALL YOU. WE ARE INTERVIEWING MANY PEOPLE ACROSS THE COUNTRY WHO HAVE READING DIFFICULTIES SO THAT SPECIAL LIBRARY SERVICES MAY BE IMPROVED. MOST OF OUR QUESTIONS ARE EASILY ANSWERED BY A YES OR NO, AND THE INTERVIEW WILL TAKE ABOUT 30 MINUTES. EVERYTHING YOU SAY IS, OF COURSE CONFIDENTIAL. NO PERSON IS EVER IDENTIFIED IN OUR REPORTS.

NOTE: If this is a proxy interview, ask Q.A and B, and fill in answers to Q.C and D.
If not a proxy interview, go to yellow Section I (next page) and begin the interview.

(For Proxy Interview:)

A. WHAT IS YOUR NAME? _____

B. WHAT IS YOUR RELATIONSHIP TO (name of handicapped person)? _____ 23 -

C. REASON FOR PROXY INTERVIEW: _____ 24 -
_____ 25 -
_____ 26 -
_____ 27 -

D. Sex: Male 28 -1
Female -2

(Continue with Yellow Section I - Next Page) _____ 79 -1
/END CARD 1/ 80 -1

SECTION I - FOR EVERYONE

TO BEGIN, I'D LIKE TO GET AN IDEA OF WHAT YOUR (HIS/HER) READING DIFFICULTY IS. I'M GOING TO READ A SERIES OF QUESTIONS ABOUT READING PROBLEMS, AND I'D LIKE YOU TO TELL ME WHICH ANSWER APPLIES TO YOU (HIM/HER).

/ VISUAL PROBLEMS /

1A. EVEN WITH GLASSES ON, ARE YOU (IS HE/SHE) UNABLE, OR ABLE TO SEE WELL ENOUGH TO READ ORDINARY NEWSPAPER PRINT?

(Skip to Q.2A) ← Unable 11 -1

(Ask Q.1B) ← Able -2

1B. WITH GLASSES ON, IF NEEDED, DO YOU (DOES HE/SHE) HAVE DIFFICULTY, OR NO DIFFICULTY SEEING WELL ENOUGH TO READ ORDINARY NEWSPAPER PRINT?

Difficulty 12 -1
No difficulty -2

/PHYSICAL PROBLEMS/

2A. WITHOUT USING ANY AIDS, ARE YOU (IS HE/SHE) UNABLE, OR ABLE TO...(read off and record in grid below)

2B. (For those activities in Q.2A that respondent is able to do, ask:) DO YOU (DOES HE/SHE) FIND IT DIFFICULT, OR NOT DIFFICULT TO...(read off and record below)

	Q.2A		Q.2B	
	Unable	Able	Difficult	Not Difficult
HOLD A BOOK OR MAGAZINE	13 -1	-2	17 -1	-2
TURN THE PAGES OF A BOOK OR MAGAZINE	14 -1	-2	18 -1	-2
SIT UP TO READ	15 -1	-2	19 -1	-2
READ FOR MORE THAN A SHORT TIME WITHOUT BECOMING WEAK OR FATIGUED	16 -1	-2	20 -1	-2

/OTHER PROBLEMS/

3. ARE YOU (IS HE/SHE) UNABLE TO READ WELL BECAUSE OF DIFFICULTIES LIKE...(read off)

	Yes	No
REVERSING LETTERS OR WORDS	21 -1	-2
FOLLOWING ALONG A LINE OF PRINT	22 -1	-2
FOLLOWING INSTRUCTIONS WITH SEVERAL STEPS	23 -1	-2

NOTE TO INTERVIEWER: If "Yes" to any of Q.3, ask Q.3A.

If "No" to all in Q.3, skip to Q.4.

3A. COULD YOU EXPLAIN THE PROBLEM A BIT? 24 -

_____ 25 -

_____ 26 -

_____

4. DO YOU (DOES HE/SHE) HAVE ANY OTHER PROBLEMS WHICH CAUSE DIFFICULTY IN READING OR USING REGULAR PRINT MATERIALS?

(Ask Q.4A) ← Yes 27 -1

(Skip to note before Q.5A) ← No -2

4A. WHAT ARE THOSE PROBLEMS? (Probe fully)

_____ 28 -

_____ 29 -

_____ 30 -

_____ 31 -

(Continued on Page 3)

SECTION I - FOR EVERYONE - Continued...

4B. (If not mentioned, or unable to explain, probe:) HOW DOES IT CAUSE DIFFICULTY IN READING OR USING REGULAR PRINT MATERIALS?

_____ 32 -

_____ 33 -

NOTE TO INTERVIEWER: If person has a reading problem (inability, difficulty or "Yes" to Any Question--1A, 1B, 2A, 2B, 3 or 4), continue with Q.5A.

If there is no reading problem (no reading difficulties or inabilities to all questions--1A, 1B, 2A, 2B, 3 or 4), verify the information on the screening questionnaire. Ask if there is a different member of the household with a reading problem. If so, begin again with that person. If not, terminate. Terminate also with persons who are deaf only.

5A. AT ABOUT WHAT AGE DID YOU (HE/SHE) BEGIN TO HAVE DIFFICULTY READING OR USING REGULAR PRINT MATERIALS?

(Ask Q.5B) ← _____ years old 34 -

(Skip to note before Q.6A) ← From birth/all my life 35 -1

5B. DID THE PROBLEM COME ON GRADUALLY OR ALL OF A SUDDEN?

Gradually 36 -1
All of a sudden -2

5C. WAS IT DUE TO AN ACCIDENT OF SOME SORT?

Yes 37 -1
No -2

NOTE TO INTERVIEWER:
- -If person has a visual problem (an inability or difficulty in Q.1A or 1B), continue with Q.6A.
- -If person does not have a visual problem, but has a physical problem (an inability or difficulty in Q.2A or 2B), skip to Q.7.
- -Some persons may have both a visual and a physical problem and should answer both series of questions, beginning with Q.6A and Q.7.
- -If person has neither a visual or physical problem but has some other problem only ("Yes" to any of Q.3 or Q.4), skip to Q.8A.

/For persons with visual problems:/

6A. NOW I'D LIKE TO ASK YOU A FEW SPECIFIC QUESTIONS ABOUT YOUR (HIS/HER) VISUAL PROBLEM IF I MAY. CAN YOU (HE/SHE) SEE WELL ENOUGH TO TELL IF A LIGHT IS ON OR OFF?

(Continue with Q.6B) ← Yes 38 -1

(Skip to Q.6E) ← No -2

6B. CAN YOU (HE/SHE) SEE WELL ENOUGH TO IDENTIFY COLORS?

Yes 39 -1
No -2

6C. DO YOU (DOES HE/SHE) USE EYE GLASSES, CONTACT LENSES, OR OTHER AIDS FOR SEEING?

(Ask Q.6D) ← Yes 40 -1

(Skip to Q.6E) ← No -2

6D. WHAT TYPE OF GLASSES OR AIDS DO YOU (DOES HE/SHE) USE?

_____ 41 -

_____ 42 -

(Continued on Page 4)

SECTION I - FOR EVERYONE - Continued...

6E. ARE YOU (IS HE/SHE) CONSIDERED LEGALLY BLIND?

Yes 43 -1
No -2

6F. IS YOUR (HIS/HER) VISUAL PROBLEM CAUSED BY...(read off)

	Yes	No
CATARACTS	44 -1	-2
DIABETES	45 -1	-2
GLAUCOMA	46 -1	-2
AN EYE INJURY	47 -1	-2

6G. IS THERE ANYTHING ELSE THAT YOU (HE/SHE) FEEL(S) HAS CAUSED YOUR (HIS/HER) VISUAL PROBLEM WITH READING?

_____ 48 -

_____ 49 -

_____ 50 -

_____ 51 -

_____ 52 -

_____ 53 -

_____ 54 -

NOTE TO INTERVIEWER: If person also has a physical problem (an inability or difficulty in Q.2A or 2B), continue with Q.7. Otherwise, skip to Q.8A.

/For persons with physical problems:/

7. NOW, I'M GOING TO READ A LIST OF PHYSICAL PROBLEMS THAT CAN CAUSE READING DIFFICULTIES. AS I READ EACH ONE, PLEASE ANSWER "YES" IF IT APPLIES TO YOU (HIM/HER), "NO" IF IT DOESN'T. (Record, in addition, any disease or problem if volunteered).

	Yes	No
EFFECTS OF A STROKE	55 -1	-2
HEART TROUBLE OR HIGH BLOOD PRESSURE	56 -1	-2
MUSCULAR OR NERVOUS DISORDER	57 -1	-2
REPEATED SPINAL OR BACK PROBLEMS	58 -1	-2
ARTHRITIS, STIFFNESS, OR MALFORMATION OF FINGERS, HANDS, ARMS, NECK OR BACK	59 -1	-2
ABSENCE OF FINGERS, HANDS OR ARMS	60 -1	-2
PARALYSIS OF ONE OR BOTH ARMS	61 -1	-2
PARALYSIS OF ONE SIDE OR UPPER HALF OF BODY	62 -1	-2
ANY OTHER PARALYSIS	63 -1	-2
CEREBRAL PALSY OR OTHER PALSY	64 -1	-2

Other (volunteered)_____ 65 -
66 -

7A. IS THERE ANY OTHER PHYSICAL PROBLEM THAT MAKES IT DIFFICULT FOR YOU (HIM/HER) TO READ? (Record disease or problem)

_____ 67 -

_____ 68 -

_____ 69 -

_____ 70 -

(Continued on Page 5)

SECTION I - FOR EVERYONE - Continued...

(Ask everyone:)

8A. ARE YOU (IS HE/SHE) HARD OF HEARING?

(Ask Q.8B) ←	Yes	71	-1
(Skip to Q.8C) ←	No		-2

8B. ARE YOU (IS HE/SHE) TOTALLY DEAF?

Yes	72	-1
No		-2

8C. ASIDE FROM THE READING PROBLEM(S) YOU'VE JUST MENTIONED, DO YOU (DOES HE/SHE) NOW HAVE ANY OTHER SERIOUS PHYSICAL PROBLEMS?

(Ask Q.8D) ←	Yes	73	-1
(Skip to Q.9) ←	No		-2

8D. WHAT IS THAT PROBLEM? (Probe fully)

_____ 74 -

_____ 75 -

_____ 76 -

_____ 77 -

79 -0

/END CARD 2/ 80 -2

9. NEXT, PLEASE ANSWER "YES" OR "NO" TO THE FOLLOWING QUESTIONS ON HOW YOU (HE/SHE) GET(S) AROUND. DO YOU (DOES HE/SHE)...(read off)

	Yes	No
A) HAVE TO STAY IN BED ALL OR MOST OF THE TIME?	11 -1	-2
B) HAVE TO STAY IN THE HOUSE ALL OR MOST OF THE TIME?	12 -1	-2
C) NEED THE ASSISTANCE OF ANOTHER PERSON TO GET AROUND?	13 -1	-2
D) NEED THE ASSISTANCE OF SOME SPECIAL AID, SUCH AS A LONG CANE OR SUPPORT, SEEING EYE DOG, WHEELCHAIR OR WALKER?	14 -1	-2

NOTE: If "Yes" to any of the above, skip to Q.10. Otherwise, continue with Q.9E and F.

E) DO YOU (DOES HE/SHE) HAVE SOME DIFFICULTY GETTING AROUND BUT NOT NEED THE ASSISTANCE OF AN AID?	15 -1	-2
F) DO YOU (DOES HE/SHE) HAVE ANY DIFFICULTY GETTING AROUND BY YOURSELF (HIMSELF/HERSELF)?	16 -1	-2

10. NOW, CONSIDERING YOUR (HIS/HER) OVERALL STATE OF WELL-BEING, WOULD YOU SAY THAT YOUR (HIS/HER) GENERAL HEALTH IS...(read off)

GOOD	17	-1
FAIR		-2
POOR		-3

11. NOW LET'S CHANGE SUBJECTS AND TALK ABOUT YOUR (HIS/HER) INTERESTS AND USE OF SPARE TIME. FIRST OF ALL, AT THE PRESENT TIME, DO YOU (DOES HE/SHE) LIVE... (read off--circle all that apply)

ALONE	18	-1
WITH HUSBAND/WIFE	19	-1
WITH CHILDREN	20	-1
WITH PARENTS	21	-1
WITH OTHER FAMILY	22	-1
WITH FRIENDS	23	-1

(Do not read) ← Other (specify)_____ 24 -

25 -

(Continued on Page 6)

SECTION I - FOR EVERYONE - Continued...

12. DO YOU (DOES HE/SHE) HAVE ANY SPECIAL INTERESTS OR HOBBIES?

(Ask Q.12A) ←— Yes 26 -1

(Skip to Q.13A) ←— No -2

12A. WHAT ARE THEY? _____ 27 -

_____ 28 -
29 -
30 -
_____ 31 -
32 -
_____

_____

13A. NEXT I'M GOING TO READ YOU A LIST OF ACTIVITIES OR THINGS TO DO. AS I READ EACH ONE, PLEASE TELL ME WHETHER YOU (HE/SHE) ENJOY(S) THAT ACTIVITY A LOT, A LITTLE, OR NOT VERY MUCH AT ALL. (Read off and record in grid below.)

13B. PLEASE TELL ME WHICH OF THESE THINGS YOU HAVE (HE/SHE HAS) DONE IN THE LAST MONTH OR SO. (Read off and record in grid below.)

	Q.13A - Enjoy			Q.13B Done in last month	
	A Lot	A Little	Not Much	Yes	No
COOKING A MEAL	33 -1	-2	-3	41 -1	-2
READING OR LISTENING TO A NEWSPAPER, MAGAZINE OR BOOK	34 -1	-2	-3	42 -1	-2
GOING SHOPPING	35 -1	-2	-3	43 -1	-2
GOING OUT--LIKE TO DINNER OR A MOVIE	36 -1	-2	-3	44 -1	-2
PLAYING GAMES LIKE CARDS OR SCRABBLE	37 -1	-2	-3	45 -1	-2
ATTENDING MEETINGS OF CLUBS OR ORGANIZATIONS	38 -1	-2	-3	46 -1	-2
WALKING FOR PLEASURE	39 -1	-2	-3	47 -1	-2
GOING TO CHURCH OR RELIGIOUS SERVICES	40 -1	-2	-3	48 -1	-2

14. ABOUT HOW OFTEN DO YOU (DOES HE/SHE) VISIT WITH, OR TALK ON THE PHONE WITH, FRIENDS OR OTHERS FROM OUTSIDE YOUR (HIS/HER) HOME? (Read off...)

SEVERAL TIMES A DAY	49 -1	
EVERY DAY		-2
SEVERAL TIMES A WEEK		-3
ONCE A WEEK		-4
SEVERAL TIMES A MONTH		-5
ONCE A MONTH		-6
LESS THAN ONCE A MONTH		-7
NEVER		-8

NOW I'D LIKE TO TALK ABOUT TV AND RADIO.

15A. ON AN AVERAGE DAY, ABOUT HOW MANY HOURS DO YOU (DOES HE/SHE) NOW SPEND WATCHING OR LISTENING TO TV?

_____Hours	50 -	
Don't watch or listen	51	-1

15B. ABOUT HOW MANY HOURS A DAY DO YOU (DOES HE/SHE) NOW SPEND LISTENING TO THE RADIO?

_____Hours	52 -	
Don't listen	53	-1

15C. DO YOU (DOES HE/SHE) FEEL THAT, IN GENERAL, THE PEOPLE THAT ARE ON TV OR THE RADIO TALK...(read off)

TOO SLOWLY	54 -1	
ABOUT THE RIGHT SPEED		-2
TOO FAST		-3

(Continued on Page 7)

SECTION I - FOR EVERYONE - Continued...

16. INCLUDING FAMILY AND FRIENDS, AS WELL AS MEDIA, WHERE DO YOU (DOES HE/SHE) GET MOST OF YOUR (HIS/HER) INFORMATION ABOUT WHAT'S GOING ON IN THE WORLD AND ACROSS THE COUNTRY?

55 -
_____ 56 -
57 -
_____ 58 -

17A. NOW, AS I READ THE FOLLOWING LIST OF MACHINES, PLEASE TELL ME WHICH ONES YOU ARE (HE/SHE IS) PHYSICALLY ABLE TO OPERATE TOTALLY BY YOURSELF (HIMSELF/HERSELF). (Read off and record in grid below.)

17B. WHICH OF THESE MACHINES ARE PRESENTLY IN YOUR (HIS/HER) HOME? (Read off and record in grid below).

	Q.17A Operate		Q.17B In Home	
	Yes	No	Yes	No
TV	59 -1	-2	66 -1	-2
RADIO	60 -1	-2	67 -1	-2
RECORD PLAYER	61 -1	-2	68 -1	-2
CASSETTE PLAYER	62 -1	-2	69 -1	-2
REEL-TO-REEL TAPE RECORDER	63 -1	-2	70 -1	-2
CB RADIO	64 -1	-2	71 -1	-2
HAM RADIO	65 -1	-2	72 -1	-2

79 -0
/END CARD 3/ 80 -3

18A. IN THE PAST FOUR MONTHS, HAVE YOU (HAS HE/SHE) SPENT ANY TIME AT ALL READING, LISTENING TO RECORDINGS OF BOOKS OR MAGAZINES ON RECORDS OR CASSETTE TAPES, OR HAVING OTHER PEOPLE READ TO YOU (HIM/HER)?

(Continue with Q.18B) ← Yes 11 -1

(Skip to Q.22) ← No -2

18B. APPROXIMATELY HOW MANY HOURS A WEEK DO YOU (DOES HE/SHE) SPEND READING, LISTENING TO RECORDINGS OF PRINTED MATERIALS, AND HAVING OTHER PEOPLE READ TO YOU (HIM/HER)? 12 -

_____ Hours 13 -

(Continued on Page 8)

SECTION I - FOR EVERYONE - continued...

19A. NOW, I WOULD LIKE TO ASK YOU ABOUT THE SPECIFIC WAYS THAT YOU READ (HE/SHE READS). IN THE PAST FOUR MONTHS, HAVE YOU (HAS HE/SHE) READ, IN WHOLE OR IN PART, ANY...(read off and record in grid below under Q.19A.)

19B. (For each item used in Q.19A, ask:--unless otherwise indicated) WHERE DID YOU (HE/SHE) GET THE (item used)? I MEAN, DID YOU (HE/SHE) GET THEM FROM AN ORGANIZATION, FROM A STORE, A LIBRARY, A SCHOOL, A BOOK CLUB, A CHURCH GROUP, AN AGENCY, OR WHERE? (Please get complete explanation of organization. Record in grid below under Q.19B.)

	Q.19A Yes	Q.19A No	Q.19B Source/Organization etc. (Fill in completely)	
NEWSPAPERS READ TO YOU (HIM/HER) BY SOMEONE ELSE	14 -1	-2	DO NOT ASK THIS QUESTION	
MAGAZINES READ TO YOU (HIM/HER) BY SOMEONE ELSE	15 -1	-2		
BOOKS READ TO YOU (HIM/HER) BY SOMEONE ELSE	16 -1	-2		
NEWSPAPERS IN REGULAR PRINT READ BY YOU (HIM/HER)	17 -1	-2		
MAGAZINES IN REGULAR PRINT READ BY YOU (HIM/HER)	18 -1	-2		
BOOKS IN REGULAR PRINT READ BY YOU (HIM/HER)	19 -1	-2		
PRINT Do not ask of totally blind--("No" to Q.6A) NEWSPAPERS IN LARGE PRINT	20 -1	-2		32 - 33 - 34 - 35 -
MAGAZINES IN LARGE PRINT	21 -1	-2		36 - 37 - 38 - 39 -
BOOKS IN LARGE PRINT	22 -1	-2		40 - 41 - 42 - 43 -
SPOKEN VERSIONS Do not ask of totally deaf persons ("Yes" to Q.8B) RECORDS OF MAGAZINES	23 -1	-2		44 - 45 - 46 - 47 -
RECORDS OF BOOKS	24 -1	-2		48 - 49 - 50 - 51 -
TAPE CASSETTES OF MAGAZINES	25 -1	-2		52 - 53 - 54 - 55 -
TAPE CASSETTES OF BOOKS	26 -1	-2		56 - 57 - 58 - 59 -
BOOKS AND OTHER MATERIALS OVER THE RADIO	27 -1	-2		60 - 61 - 62 - 63 -
BRAILLE Ask only of persons with visual problems--(Q.1A or Q.1B) BRAILLE MAGAZINES	28 -1	-2		64 - 65 - 66 - 67 -
BRAILLE BOOKS	29 -1	-2		68 - 69 - 70 - 71 -
OTHER BRAILLE MATERIALS	30 -1	-2		72 - 73 - 74 - 75 -
(Probe:) ANYTHING ELSE? _____	31 -			76 - 77 -
			/END CARD 4/	79 -0 80 -4

(Continued on Page 9)

SECTION I - FOR EVERYONE - Continued...

NOTE: If respondent answers "No" to all Braille materials in Q.19A, ask Q.20A. Otherwise, skip to Q.21A.

20A. HAVE YOU (HAS HE/SHE) EVER HAD ANY INSTRUCTION IN BRAILLE?

(Ask Q.20B) ← Yes 11 -1

(Skip to Q.21A) ← No -2

20B. WILL YOU TELL ME ANY REASONS WHY YOU ARE (HE/SHE IS) NO LONGER USING BRAILLE?

_____ 12 -

_____ 13 -

_____ 14 -

_____ 15 -

21A. WHICH OF THE FOLLOWING WAYS TO READ DO YOU (DOES HE/SHE) USE MOST OFTEN? (Read off and record first mention in grid below.)

21B. WHICH DO YOU (DOES HE/SHE) USE SECOND MOST OFTEN? (Record in grid below.)

	Q.21A Most Often	Q.21B--2nd Most Often
REGULAR PRINT	16 -1	18 -1
LARGE PRINT	-2	-2
SOMEONE ELSE READING TO YOU (HIM/HER)	-3	-3
RECORDED VERSIONS	-4	-4
BRAILLE	-5	-5
(Do not read) ← Other (specify)_____	17 -	_____19-

22. ON THE WHOLE, WOULD YOU SAY THAT YOU ARE (HE/SHE IS) PRESENTLY READING...(read off)

MUCH LESS THAN YOU (HE/SHE) WOULD LIKE 20 -1
SOMEWHAT LESS THAN YOU (HE/SHE) WOULD LIKE -2
OR AS MUCH AS YOU (HE/SHE) WOULD LIKE -3

NOTE TO INTERVIEWER: If person was handicapped before the age of seven (refer to Q.5A, Page 3), skip to Q.24. Otherwise, continue with Q.23A.

23A. COMPARED TO BEFORE YOU (HE/SHE) HAD DIFFICULTY READING OR USING REGULAR PRINT MATERIALS, ARE YOU (IS HE/SHE) PRESENTLY READING...(read off)

MUCH MORE NOW 21 -1
ABOUT THE SAME -2
OR MUCH LESS NOW -3

23B. ARE THE MATERIALS SHORTER, ABOUT THE SAME LENGTH, OR ARE THEY LONGER THAN THOSE READ PREVIOUSLY?

Shorter length 22 -1
Same length -2
Longer length -3

23C. WERE YOU (WAS HE/SHE) ACCUSTOMED TO USING LIBRARIES BEFORE YOU (HE/SHE) HAD A PROBLEM USING REGULAR PRINT?

Yes 23 -1
No -2

24. DO YOU (DOES HE/SHE) EVER DISCUSS BOOKS OR MAGAZINES WITH FRIENDS OR FAMILY?

Yes 24 -1
No -2

(Continued on Page 10)

SECTION I - FOR EVERYONE - Continued...

25. DO YOU (DOES HE/SHE) FEEL THAT BOOKS CONTAINING STRONG LANGUAGE SHOULD BE AVAILABLE IN LIBRARIES, SHOULD BE AVAILABLE ONLY WITH WARNINGS, OR SHOULD NOT BE MADE AVAILABLE IN LIBRARIES? (Record below. Repeat for each subject in list.)

	Should be Available	Only with warnings	Should not be available
STRONG LANGUAGE	25 -1	-2	-3
EXTREME VIOLENCE	26 -1	-2	-3
EXPLICIT SEX	27 -1	-2	-3
EXTREMIST ATTITUDES	28 -1	-2	-3

26. NEXT, I'D LIKE TO GO OVER A LIST OF READING SUBJECTS WITH YOU. WOULD YOU PLEASE TELL ME WHICH OF THESE YOU ARE (HE/SHE IS) ESPECIALLY INTERESTED IN BY ANSWERING YES OR NO. (Read off. If respondent says "A little" or "Somewhat", this is a "No" answer.)

	Yes	No
CURRENT EVENTS AND COMMENTARY	29 -1	-2
SPORTS	30 -1	-2
BIBLE AND RELIGION	31 -1	-2
PSYCHOLOGY, SOCIOLOGY, PERSONAL PROBLEMS	32 -1	-2
DO-IT-YOURSELF MANUALS, COOKBOOKS, REFERENCE, ETC.	33 -1	-2
BUSINESS	34 -1	-2
NATURE	35 -1	-2
TRAVEL	36 -1	-2
SCIENCE	37 -1	-2
HISTORY	38 -1	-2
POETRY	39 -1	-2
PLAYS	40 -1	-2
HUMOR	41 -1	-2
SHORT STORIES	42 -1	-2
SCIENCE FICTION	43 -1	-2
MYSTERIES	44 -1	-2
WESTERNS	45 -1	-2
CHILDREN'S BOOKS	46 -1	-2
SCHOOL BOOKS AND TEXTS	47 -1	-2
BEST SELLERS	48 -1	-2
CURRENT NOVELS	49 -1	-2
CLASSIC NOVELS	50 -1	-2

26A. ARE THERE ANY OTHER SUBJECTS WHICH WE HAVEN'T MENTIONED THAT YOU ARE (HE/SHE IS) PARTICULARLY INTERESTED IN?

_____ 51 -

_____ 52 -

_____ 53 -

_____ 54 -

(Continued on Page 11)

SECTION I - FOR EVERYONE - Continued...

27. NEXT, I WANT TO ASK A FEW QUESTIONS ABOUT PEOPLE WHO MAY HELP YOU (HIM/HER) WITH READING MATERIALS. DOES ANYONE...(read off)

	Yes	No
SELECT MATERIALS FOR YOU (HIM/HER) TO READ	55 -1	-2
WRITE FOR THINGS FOR YOU (HIM/HER)	56 -1	-2
GO TO THE POST OFFICE TO SEND THINGS OFF	57 -1	-2
GET MATERIALS THAT YOU (HE/SHE) ASK(S) FOR	58 -1	-2
MAKE RECORDINGS FOR YOU (HIM/HER)	59 -1	-2
HELP PUT ON RECORDS OR TAPES	60 -1	-2
HELP WITH ANYTHING ELSE	61 -1	-2

(Specify)_____ 62 -
63 -
64 -
65 -

NOTE: If "No" to all in Q.27, ask Q.28.
If "Yes" to any, skip to Q.29.

28. IF YOU (HE/SHE) NEED(S) HELP WITH ANY OF THESE THINGS, DO YOU (DOES HE/SHE) HAVE A NEIGHBOR OR ANYONE TO CALL?

(Now skip to Q.31) ←	Yes	66 -1
	No	-2
	Don't need	-3

29. WHO USUALLY HELPS YOU (HIM/HER): DO YOU (DOES HE/SHE) USUALLY USE...(read off)

		Yes	No
(Ask Q.30) ←	VOLUNTEERS	67 -1	-2
(Skip to Q.31) ←	SOMEBODY IN THE HOUSE	68 -1	-2
	FRIEND OR NEIGHBOR	69 -1	-2
	OR PAID READER	70 -1	-2

(Do not read) ← Other (specify below)

_____ 71 -
72 -
73 -
74 -

30. HOW DO YOU (DOES HE/SHE) GET THESE VOLUNTEERS, AND WHERE DO THEY COME FROM? (Probe for complete explanation of organizations)

_____ 75 -
_____ 76 -
_____ 77 -
_____ 78 -
(Now skip to Q.32)

_____ 79 -0
/END CARD 5/ 80 -5

31. HOW INTERESTED WOULD YOU (HE/SHE) BE IN HAVING VOLUNTEERS READ TO YOU (HIM/HER) OR HELPING YOU (HIM/HER) WITH READING MATERIALS? WOULD YOU SAY...(read off)

VERY INTERESTED	11 -1
SOMEWHAT INTERESTED	-2
NOT VERY INTERESTED	-3
OR NOT AT ALL INTERESTED	-4

(Continued on Page 12)

SECTION I - FOR EVERYONE - Continued...

32. HAVE YOU (HAS HE/SHE) EVER HEARD ABOUT THE "TALKING BOOK" AND BRAILLE PROGRAM? BY THAT, I MEAN SPOKEN VERSIONS OF BOOKS AND MAGAZINES ON RECORDS AND TAPES, AND BRAILLE MATERIALS PREPARED BY THE LIBRARY OF CONGRESS?

Yes (Continue with Q.33A)	12	-1
No (Skip to next section--GREEN SECTION II--Non-users)		-2
Don't know (Skip to next section--GREEN SECTION II--Non-users)		-3

33A. HOW DID YOU (HE/SHE) FIRST HEAR ABOUT THE TALKING BOOK AND BRAILLE PROGRAM?

_____ 13 -

_____ 14 -

NOTE TO INTERVIEWER: If answer to Q.33A indicates that the first time was through the recent Trendex letter sent to respondents announcing your call, skip to next section--GREEN SECTION II - NON-USERS.

If answer is "Friend or Relative" or other individual, ask Q.33B.

If answer is other than Trendex letter or friend/relative, skip to Q.34.

33B. DOES (person mentioned in Q.33A) USE THE PROGRAM?

Yes	15	-1
No		-2

34. HAVE YOU (HAS HE/SHE) EVER ORDERED OR RECEIVED TALKING BOOKS OR MAGAZINES OR ANY BRAILLE MATERIALS FROM A LIBRARY?

Yes (Continue with Q.35)	16	-1
No (Skip to next section--GREEN SECTION II--Non-users)		-2
Don't know (Skip to next section--GREEN SECTION II--Non-users)		-3

35. ABOUT HOW LONG AGO DID YOU (HE/SHE) LAST ORDER OR RECEIVE ANYTHING FROM A LIBRARY? WAS IT (read off)...

LESS THAN ONE YEAR AGO (Go to PINK SECTION III--Current Users)	17	-1
OR ONE YEAR AGO OR MORE (Go to BLUE SECTION IV--Former Users)		-2
(Do not read) Don't know/don't remember (Go to BLUE SECTION IV--Former Users)		-3

79 -0

/END CARD 6/ 80 -6

SECTION II - NON-USERS

(For persons who have never used the Talking Book or Braille Program of the Library of Congress)

1. ARE YOU FAMILIAR WITH HOW THE TALKING BOOK AND BRAILLE PROGRAM OF THE LIBRARY OF CONGRESS WORKS?

(Skip to Q.2) ← Yes 11 -1

(Continue with description of program) ← No -2

Description of Program:

THE PROGRAM WORKS LIKE THIS. FREE BOOKS AND MAGAZINES ON RECORDS AND CASSETTE TAPES ARE SENT TO YOU (HIM/HER) THROUGH THE MAIL, ALONG WITH A FREE RECORD PLAYER OR CASSETTE PLAYER, AND EARPHONES. SPECIAL REMOTE ON-OFF SWITCHES AND PILLOW PHONES FOR PERSONS WITH RESTRICTED MOBILITY ARE ALSO AVAILABLE. BRAILLE BOOKS AND MAGAZINES ARE AVAILABLE, AS WELL AS MUSIC SCORES AND INSTRUCTIONS FOR MUSICIANS. LARGE PRINT MATERIALS MAY BE AVAILABLE, DEPENDING ON YOUR LIBRARY. THE APPLICATION IS PRETTY SIMPLE. YOU CHECK (HE/SHE CHECKS) OFF ON A MAIL FORM THE SPECIFIC BOOKS OR MAGAZINES YOU WANT (HE/SHE WANTS), OR BROAD SUBJECT AREAS THAT INTEREST YOU (HIM/HER), AND SEND IN THE FORM. OR, YOU (HE/SHE) CAN PHONE IN YOUR (HIS/HER) REQUESTS. THE SERVICE DOES NOT DEPEND ON INCOME AND IS FREE FOR ALL.

2. ALTHOUGH IT'S HARD TO SAY WITHOUT TRYING IT, HOW INTERESTED DO YOU THINK YOU (HE/SHE) WOULD BE IN BORROWING TALKING BOOKS AND MAGAZINES OR BRAILLE MATERIALS--DO YOU THINK YOU (HE/SHE) WOULD BE...(read off)

(Ask Q.3) ← VERY INTERESTED 12 -1
SOMEWHAT INTERESTED -2

(Skip to Q.4) ← NOT VERY INTERESTED -3
NOT AT ALL INTERESTED -4

3. WHICH OF THE FOLLOWING MATERIALS DO YOU THINK YOU WOULD LIKE TO TRY? (Read off)...

		Yes	No
(Do not ask of deaf persons) ←	TALKING BOOKS ON RECORDS	13 -1	-2
	TALKING BOOKS ON CASSETTES	14 -1	-2
	TALKING MAGAZINES ON RECORDS	15 -1	-2
	TALKING MAGAZINES ON CASSETTES	16 -1	-2
	HEAD PHONES	17 -1	-2
	PILLOW PHONES	18 -1	-2
	REMOTE ON-OFF SWITCHES	19 -1	-2
(Do not ask of totally blind) ←	LARGE PRINT BOOKS	20 -1	-2
	LARGE PRINT MAGAZINES	21 -1	-2
(Ask only of persons with visual problems) ←	BRAILLE BOOKS	22 -1	-2
	BRAILLE AND LARGE PRINT MUSIC SCORES AND INSTRUCTIONS FOR MUSICIANS	23 -1	-2

4. CAN YOU FORESEE ANY PROBLEMS IN YOUR USING THIS SERVICE, OR REASONS WHY YOU WOULD NOT WANT TO TRY IT? (Probe)

_____ 24 -
25 -
_____ 26 -
27 -
_____ 28 -
29 -

79 -0
80 -7

NOW GO TO BUFF - SECTION V /END CARD 7/

SECTION III - CURRENT USERS

(For persons who have used the Library of Congress service within the last year.)

1. NOW I'D LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR (HIS/HER) USE OF THE TALKING BOOK AND BRAILLE PROGRAM. FOR HOW LONG A TIME HAVE YOU (HAS HE/SHE) BEEN USING IT? (Do not read)

Less than 3 months	11 -1
3 months to a year	-2
1 - 5 years	-3
More than 5 years	-4

NOTE TO INTERVIEWER: If person is totally deaf, skip to note before Q.15A. Otherwise, continue with Q.2.

2. HAVE YOU (HAS HE/SHE) LISTENED TO ANY TALKING BOOKS OR MAGAZINES WITHIN THE PAST YEAR?

Yes ——→ (Continue with Q.3A)	12 -1
No ——→ (Skip to Q.14A on Page 16)	-2

3A. WHAT DO YOU (DOES HE/SHE) THINK OF THE TALKING BOOKS AND MAGAZINES...FOR EXAMPLE...(read off)

	Yes	No
IS THERE ENOUGH VARIETY OF TOPICS AVAILABLE	13 -1	-2
ARE THERE ENOUGH DIFFERENT BOOKS AND MAGAZINES WITHIN EACH TOPIC	14 -1	-2
ARE THE BOOKS AND MAGAZINES CURRENT ENOUGH	15 -1	-2
ARE THEY TOO DIFFICULT IN LANGUAGE	16 -1	-2
ARE THEY OF A GOOD SOUND QUALITY	17 -1	-2

3B. ABOUT HOW MANY HOURS PER WEEK DO YOU ESTIMATE YOU (HE/SHE) LISTEN(S) TO TALKING BOOKS AND MAGAZINES?

_____ hours 18 -
19 -

4. DO YOU (DOES HE/SHE) PRESENTLY HAVE (read off)...

	Yes	No
A RECORD PLAYER FROM THE LIBRARY	20 -1	-2
A CASSETTE PLAYER FROM THE LIBRARY	21 -1	-2

NOTE: If person has neither machine, skip to Q.8.
Ask Q.5 through Q.7 for each machine person has in Q.4.

5. WOULD YOU SAY THAT YOUR (HIS/HER) (RECORD PLAYER)(CASSETTE PLAYER) IS IN EXCELLENT, GOOD, FAIR OR POOR CONDITION?

	Record Player	Cassette Player
Excellent	22 -1	23 -1
Good	-2	-2
Fair	-3	-3
Poor	-4	-4

6. HOW LONG DID IT TAKE YOU (HIM/HER) TO GET YOUR (HIS/HER) (RECORD PLAYER)(CASSETTE PLAYER) AFTER IT WAS ORDERED? (Specify days, weeks or months)

Record Player		Cassette Player	
	24 -		28 -
	25 -		29 -
_____	26 -	_____	30 -
	27 -		31 -

(Continued on Page 15)

SECTION III - CURRENT USERS - Continued...

7. HOW DO YOU (DOES HE/SHE) THINK THE (RECORD PLAYER) (CASSETTE PLAYER) COULD BE IMPROVED?

Record Player:_____ 32 -
33 -
_____ 34 -
35 -
_____ 36 -
37 -

Cassette Player:_____ 38 -
39 -
_____ 40 -
41 -
_____ 42 -
43 -

8. HOW OFTEN DO YOU (DOES HE/SHE) USE THE BI-MONTHLY MAGAZINE CALLED TALKING BOOK TOPICS, WHICH DESCRIBES NEW TALKING BOOKS THAT ARE AVAILABLE? (Read off)...

(Continue with Q.9) ←	REGULARLY	44	-1
	OCCASIONALLY		-2
	ALMOST NEVER		-3
(Skip to Q.10) ←	NEVER		-4
	(Do not read) Never received		-5

9. DO THE DESCRIPTIONS IN TALKING BOOK TOPICS...(read off)

	Yes	No
TELL YOU (HIM/HER) ENOUGH TO LET YOU (HIM/HER) KNOW WHETHER YOU (HE/SHE) WANT(S) TO ORDER BOOKS	45 -1	-2
TELL YOU (HIM/HER) ENOUGH ABOUT THE LENGTH AND DIFFICULTY OF THE BOOKS	46 -1	-2
ACCURATELY DESCRIBE BOOKS THAT YOU HAVE (HE/SHE HAS) READ	47 -1	-2

10. DO YOU (DOES HE/SHE) USUALLY...(read off)

	Yes	No
ORDER SPECIFIC BOOK TITLES	48 -1	-2
OR ASK THE LIBRARY TO SELECT THE MATERIALS	49 -1	-2

11. HOW DO YOU (DOES HE/SHE) USUALLY ORDER? (Read off)...

PERSONALLY BY TELEPHONE	50	-1
PERSONALLY BY MAIL		-2
HAVE (HAS) SOMEONE ORDER FOR YOU (HIM/HER)		-3
OR IS THERE SOME OTHER WAY		-4

(If"some other way", please specify)_____ 51 -
52 -

12. ON THE WHOLE, IS THE WAITING TIME BETWEEN ORDERING AND RECEIVING TALKING BOOKS ALL RIGHT OR TOO LONG?

All right	53	-1
Too long		-2

13. ABOUT HOW LONG WOULD YOU SAY IT USUALLY TAKES FOR YOU (HIM/HER) TO RECEIVE THE SPECIFIC MATERIALS THAT YOU (HE/SHE) ORDER(S)? (Specify days, weeks or months).

_____ 54 -
55 -
56 -
57 -

(Continued on Page 16)

SECTION III - CURRENT USERS - Continued...

14A. HOW DO YOU THINK THE TALKING BOOK PROGRAM COULD BE IMPROVED FOR YOU (HIM/HER)? (If not using, probe for reasons)

_____ 58 -

_____ 59 -

_____ 60 -

_____ 61 -

_____ 62 -

_____ 63 -

14B. WHAT OTHER READING SERVICES WOULD YOU (HE/SHE) LIKE?

_____ 64 -
65 -
_____ 66 -
67 -
_____ 68 -
69 -

NOTE TO INTERVIEWER: If person has a visual problem, continue with Q.15A
If person does not have a visual problem, skip to BUFF SECTION V.

15A. IN THE PAST YEAR, HAVE YOU (HAS HE/SHE) RECEIVED LARGE PRINT MATERIALS FROM YOUR (HIS/HER) LIBRARY?

Yes 70 -1
No -2

15B. IN THE PAST YEAR, HAVE YOU (HAS HE/SHE) RECEIVED BRAILLE MATERIALS FROM YOUR (HIS/HER) LIBRARY?

(Continue with Q.16) ← Yes 71 -1

(Skip to BUFF - SECTION V) ← No -2

(For Braille Users:)

16. WHAT DO YOU (DOES HE/SHE) THINK OF THE BRAILLE BOOKS AND MAGAZINES--FOR EXAMPLE...(read off)

	Yes	No
IS THERE ENOUGH VARIETY OF TOPICS AVAILABLE	72 -1	-2
ARE THERE ENOUGH DIFFERENT BOOKS AND MAGAZINES WITHIN EACH TOPIC	73 -1	-2
ARE THE BOOKS AND MAGAZINES CURRENT ENOUGH	74 -1	-2
ARE THEY TOO DIFFICULT IN LANGUAGE	75 -1	-2
ARE THEY OF A GOOD QUALITY OF BRAILLE--BY THAT I MEAN THE SENSITIVITY OF THE BRAILLE IMPRESSIONS ON THE PAPER, THE SPACING, AND THE USE OF CONTRACTIONS	76 -1	-2

79 -0
/END CARD 8/ 80 -8

17. HOW MANY HOURS PER WEEK DO YOU ESTIMATE YOU (HE/SHE) READ(S) LIBRARY OF CONGRESS BRAILLE BOOKS AND MAGAZINES?

_____ hours 11 -
12 -

18. ABOUT HOW OFTEN DO YOU (DOES HE/SHE) READ THE BRAILLE BOOK REVIEW, THE BI-MONTHLY MAGAZINE WHICH LISTS NEWLY AVAILABLE BRAILLE MATERIALS? (Read off)...

(Continue with Q.19) ← REGULARLY 13 -1
OCCASIONALLY -2
ALMOST NEVER -3

(Skip to Q.20) ← NEVER -4
(Do not read) Never received -5

(Continued on Page 17)

SECTION III - CURRENT USERS - Continued...

19. DO THE DESCRIPTIONS IN THE BRAILLE BOOK REVIEW...(read off)

	Yes	No
TELL YOU (HIM/HER) ENOUGH TO LET YOU (HIM/HER) KNOW WHETHER YOU (HE/SHE) WANT(S) TO ORDER BOOKS	14 -1	-2
TELL YOU (HIM/HER) ENOUGH ABOUT THE LENGTH AND DIFFICULTY OF THE BOOKS	15 -1	-2
ACCURATELY DESCRIBE BOOKS THAT YOU HAVE (HE/SHE HAS) READ	16 -1	-2

20. DO YOU (DOES HE/SHE) USUALLY...(read off)

	Yes	No
ORDER SPECIFIC BOOK TITLES	17 -1	-2
OR ASK THE LIBRARY TO SELECT THE MATERIALS	18 -1	-2

21. HOW DO YOU (DOES HE/SHE) USUALLY ORDER? (Read off)...

PERSONALLY BY TELEPHONE 19 -1
PERSONALLY BY MAIL -2
HAVE (HAS) SOMEONE ORDER FOR YOU (HIM/HER) -3
OR IS THERE SOME OTHER WAY -4

(If "Some other way", specify)_____ 20 -
21 -

22. ON THE WHOLE, IS THE WAITING TIME BETWEEN ORDERING AND RECEIVING BRAILLE MATERIALS ALL RIGHT OR TOO LONG?

All right 22 -1
Too long -2

23. ABOUT HOW LONG WOULD YOU SAY IT USUALLY TAKES FOR YOU (HIM/HER) TO RECEIVE THE SPECIFIC MATERIALS THAT YOU (HE/SHE) ORDER(S)? (Specify days, weeks or months)

_____ 23 -
24 -
25 -
26 -

24A. HOW DO YOU THINK THE BRAILLE PROGRAM COULD BE IMPROVED FOR YOU (HIM/HER)?

_____ 27 -
_____ 28 -
_____ 29 -
_____ 30 -
_____ 31 -
_____ 32 -

24B. WHAT OTHER READING SERVICES WOULD YOU (HE/SHE) LIKE?

_____ 33 -
34 -
_____ 35 -
36 -
_____ 37 -
38 -

79 -0
NOW GO TO BUFF SECTION V /END CARD 9/ 80 -9

(Continued on Page 18)

SECTION IV - FORMER USERS

(For persons who used the Library of Congress service more than one year ago, but have not used it in the past year.)

1. DO YOU REMEMBER HOW THE TALKING BOOK AND BRAILLE PROGRAM WORKS?

(Skip to Q.2) ← Yes 11 -1

(Continue with description of program) ← No -2

Description of Program:

THE PROGRAM WORKS LIKE THIS. FREE BOOKS AND MAGAZINES ON RECORDS AND CASSETTE TAPES ARE SENT TO YOU (HIM/HER) THROUGH THE MAIL, ALONG WITH A FREE RECORD PLAYER OR CASSETTE PLAYER, AND EARPHONES. SPECIAL REMOTE ON-OFF SWITCHES AND PILLOW PHONES FOR PERSONS WITH RESTRICTED MOBILITY ARE ALSO AVAILABLE. BRAILLE BOOKS AND MAGAZINES ARE AVAILABLE, AS WELL AS MUSIC SCORES AND INSTRUCTIONS FOR MUSICIANS. LARGE PRINT MATERIALS MAY BE AVAILABLE, DEPENDING ON YOUR LIBRARY. THE APPLICATION IS PRETTY SIMPLE. YOU CHECK (HE/SHE CHECKS) OFF ON A MAIL FORM THE SPECIFIC BOOKS OR MAGAZINES YOU WANT (HE/SHE WANTS), OR BROAD SUBJECT AREAS THAT INTEREST YOU (HIM/HER), AND SEND IN THE FORM. OR, YOU (HE/SHE) CAN PHONE IN YOUR (HIS/HER) REQUESTS. THE SERVICE DOES NOT DEPEND ON INCOME AND IS FREE FOR ALL.

2. SINCE YOU (HE/SHE) ONCE USED THE TALKING BOOK AND BRAILLE PROGRAM, AND NO LONGER DO, WOULD YOU PLEASE TELL ME THE MOST IMPORTANT REASON WHY YOU (HE/SHE) STOPPED USING THIS SERVICE? (Probe:) WERE THERE ANY OTHER REASONS?

12 -
_____ 13 -
14 -
_____ 15 -
16 -
17 -
_____ 18 -
19 -
_____ 20 -
21 -
_____ 22 -
23 -

NOTE TO INTERVIEWER: If any of the reasons given in Q.2 relate directly to the Library Service itself, continue with Q.3 (for example, long delays, poor quality, materials were not current, etc.)

If all reasons given in Q.2 are personal and not related to the service itself, skip to Q.25A, Page 22 (for example, poor health, prefer TV, too busy, etc.)

If there is any uncertainty, continue with Q.3.

3. WHEN WAS THE LAST TIME YOU (HE/SHE) USED THE TALKING BOOK AND BRAILLE PROGRAM? (Read off)...

(Ask Q.4) ← ONE TO THREE YEARS AGO 24 -1

(Skip to Q.25A - Page 22) ← OR MORE THAN THREE YEARS AGO -2
(Do not read) Don't know/don't remember -3

4. FOR HOW LONG A TIME DID YOU (HE/SHE) USE THE TALKING BOOK AND BRAILLE PROGRAM? (Do not read)

(Skip to Q.25B - Page 22) ← Less than 3 months 25 -1

(Continue--Read note below) ← 3 months to a year -2
1 - 5 years -3
More than 5 years -4
Don't know/don't remember -5

NOTE: If person is totally deaf, skip to note before Q.17A; otherwise, continue with Q.5.

(Continued on Page 19)

SECTION IV - FORMER USERS - Continued...

5. DID YOU (HE/SHE) USE TALKING BOOKS AND MAGAZINES?

(Continue with Q.6A) ← Yes 26 -1

(Skip to note before Q.17A) ← No -2

6A. WHAT DID YOU (HE/SHE) THINK OF THE TALKING BOOKS AND MAGAZINES...FOR EXAMPLE... (Read off)

	Yes	No
WAS THERE ENOUGH VARIETY OF TOPICS AVAILABLE	27 -1	-2
WERE THERE ENOUGH DIFFERENT BOOKS AND MAGAZINES WITHIN EACH TOPIC	28 -1	-2
WERE THE BOOKS AND MAGAZINES CURRENT ENOUGH	29 -1	-2
WERE THEY TOO DIFFICULT IN LANGUAGE	30 -1	-2
WERE THEY OF A GOOD SOUND QUALITY	31 -1	-2

6B. ABOUT HOW MANY HOURS PER WEEK DO YOU ESTIMATE YOU (HE/SHE) LISTENED TO TALKING BOOKS AND MAGAZINES?

_____ hours 32 -
33 -

7. DID YOU (HE/SHE) HAVE...(read off)

	Yes	No
A RECORD PLAYER FROM THE LIBRARY	34 -1	-2
A CASSETTE PLAYER FROM THE LIBRARY	35 -1	-2

NOTE: If person had neither machine, skip to Q.11.
Ask Q.8 through 10 for each machine person had in Q.7.

8. WOULD YOU SAY THAT YOUR (HIS/HER) (RECORD PLAYER)(CASSETTE PLAYER) WAS IN EXCELLENT, GOOD, FAIR OR POOR CONDITION?

	Record Player	Cassette Player
Excellent	36 -1	37 -1
Good	-2	-2
Fair	-3	-3
Poor	-4	-4

9. HOW LONG DID IT TAKE YOU (HIM/HER) TO GET YOUR (HIS/HER) (RECORD PLAYER)(CASSETTE PLAYER) AFTER IT WAS ORDERED? (Specify days, weeks or months)

Record Player		Cassette Player	
	38 -		42 -
	39 -		43 -
_____	40 -	_____	44 -
	41 -		45 -

10. HOW DO YOU (DOES HE/SHE) THINK THE (RECORD PLAYER)(CASSETTE PLAYER) COULD BE IMPROVED?

Record Player: _____ 46 -
47 -
_____ 48 -
49 -
_____

Cassette Player: _____ 50 -
51 -
_____ 52 -
53 -
_____

(Continued on Page 20)

SECTION IV - FORMER USERS - Continued...

11. HOW OFTEN DID YOU (HE/SHE) USE THE BI-MONTHLY MAGAZINE CALLED TALKING BOOK TOPICS, WHICH DESCRIBES NEW TALKING BOOKS THAT ARE AVAILABLE? (Read off)...

(Continue with Q.12) ←	REGULARLY	54 -1
	OCCASIONALLY	-2
	ALMOST NEVER	-3
(Skip to Q.13) ←	NEVER	-4
	(Do not read) Never received	-5

12. DID THE DESCRIPTIONS IN TALKING BOOK TOPICS...(read off)

	Yes	No
TELL YOU (HIM/HER) ENOUGH TO LET YOU (HIM/HER) KNOW WHETHER YOU (HE/SHE) WANTED TO ORDER BOOKS	55 -1	-2
TELL YOU (HIM/HER) ENOUGH ABOUT THE LENGTH AND DIFFICULTY OF THE BOOKS	56 -1	-2
ACCURATELY DESCRIBE BOOKS THAT YOU (HE/SHE) HAD READ	57 -1	-2

13. DID YOU (HE/SHE) USUALLY...(read off)

	Yes	No
ORDER SPECIFIC BOOK TITLES	58 -1	-2
OR ASK THE LIBRARY TO SELECT THE MATERIALS	59 -1	-2

14. HOW DID YOU (HE/SHE) USUALLY ORDER? (Read off)...

PERSONALLY BY TELEPHONE	60 -1
PERSONALLY BY MAIL	-2
HAD SOMEONE ORDER FOR YOU (HIM/HER)	-3
OR WAS THERE SOME OTHER WAY	-4

(If "Some other way", please specify)_____ 61 -
62 -

15. ON THE WHOLE, WAS THE WAITING TIME BETWEEN ORDERING AND RECEIVING TALKING BOOKS ALL RIGHT OR TOO LONG?

All right	63 -1
Too long	-2

16. ABOUT HOW LONG WOULD YOU SAY IT USUALLY TOOK FOR YOU (HIM/HER) TO RECEIVE THE SPECIFIC MATERIALS THAT YOU (HE/SHE) ORDERED? (Specify days, weeks or months)

_____ 64 -
65 -
66 -
67 -

NOTE TO INTERVIEWER: If person has a visual problem, continue with Q.17A.
If person does not have a visual problem, skip to Q.26A on Page 22).

17A. DID YOU (HE/SHE) RECEIVE LARGE PRINT MATERIALS FROM YOUR (HIS/HER) LIBRARY?

Yes	68 -1
No	-2

17B. DID YOU (HE/SHE) RECEIVE BRAILLE MATERIALS FROM YOUR (HIS/HER) LIBRARY?

(Continue with Q.18A) ←	Yes	69 -1
(Skip to Q.26A--Page 22) ←	No	-2

(Continued on Page 21)

SECTION IV - FORMER USERS - Continued...

For Braille Users:

18A. WHAT DID YOU (DOES HE/SHE) THINK OF THE BRAILLE BOOKS AND MAGAZINES--FOR EXAMPLE... (Read off)

	Yes	No
WAS THERE ENOUGH VARIETY OF TOPICS AVAILABLE	70 -1	-2
WERE THERE ENOUGH DIFFERENT BOOKS AND MAGAZINES WITHIN EACH TOPIC	71 -1	-2
WERE THE BOOKS AND MAGAZINES CURRENT ENOUGH	72 -1	-2
WERE THEY TOO DIFFICULT IN LANGUAGE	73 -1	-2
WERE THEY OF A GOOD QUALITY OF BRAILLE--BY THAT I MEAN THE SENSITIVITY OF THE BRAILLE IMPRESSIONS ON THE PAPER, THE SPACING, AND THE USE OF CONTRACTIONS	74 -1	-2

18B. THINKING BACK, ABOUT HOW MANY HOURS PER WEEK DO YOU ESTIMATE YOU (HE/SHE) READ BRAILLE BOOKS AND MAGAZINES THAT YOU (HE/SHE) GOT FROM YOUR (HIS/HER) LIBRARY?

_____ hours 75 -
76 -

79 -1
/END CARD 10/ 80 -0

19. ABOUT HOW OFTEN DID YOU (HE/SHE) READ THE BRAILLE BOOK REVIEW, THE BI-MONTHLY MAGAZINE WHICH LISTS NEWLY AVAILABLE BRAILLE MATERIALS? (Read off)

(Continue with Q.20) ← REGULARLY 11 -1
OCCASIONALLY -2
ALMOST NEVER -3

(Skip to Q.21) ← NEVER -4
(Do not read) Never received -5

20. DID THE DESCRIPTIONS IN THE BRAILLE BOOK REVIEW...(read off)

	Yes	No
TELL YOU (HIM/HER) ENOUGH TO LET YOU (HIM/HER) KNOW WHETHER YOU (HE/SHE) WANTED TO ORDER BOOKS	12 -1	-2
TELL YOU (HIM/HER) ENOUGH ABOUT THE LENGTH AND DIFFICULTY OF THE BOOKS	13 -1	-2
ACCURATELY DESCRIBE BOOKS THAT YOU (HE/SHE) HAD READ	14 -1	-2

21. DID YOU (HE/SHE) USUALLY...(read off)

	Yes	No
ORDER SPECIFIC BOOK TITLES	15 -1	-2
OR ASK THE LIBRARY TO SELECT THE MATERIALS	16 -1	-2

22. HOW DID YOU (HE/SHE) USUALLY ORDER? (Read off)...

PERSONALLY BY TELEPHONE 17 -1
PERSONALLY BY MAIL -2
HAD SOMEONE ORDER FOR YOU (HIM/HER) -3
OR WAS THERE SOME OTHER WAY -4

(If "Some other way", specify)_____ 18 -
19 -

23. ON THE WHOLE, WAS THE WAITING TIME BETWEEN ORDERING AND RECEIVING BRAILLE MATERIALS ALL RIGHT OR TOO LONG?

All right 20 -1
Too long -2

24. ABOUT HOW LONG WOULD YOU SAY IT USUALLY TOOK FOR YOU (HIM/HER) TO RECEIVE THE SPECIFIC MATERIALS THAT YOU (HE/SHE) ORDERED? (Specify days, weeks or months)

21 -
_____ 22 -
(Now skip to Q.26A) 23 -
24 -

(Continued on Page 22)

SECTION IV - FORMER USERS - Continued...

25A. FOR HOW LONG A TIME DID YOU (HE/SHE) USE THE TALKING BOOK AND BRAILLE PROGRAM? (Do not read)

Less than 3 months	25	-1
3 months to a year		-2
1 - 5 years		-3
More than 5 years		-4
Don't know/don't remember		-5

25B. DID YOU (HE/SHE) USE...(read off)

	Yes	No
TALKING BOOKS AND MAGAZINES	26 -1	-2
BRAILLE MATERIALS	27 -1	-2
LARGE PRINT MATERIALS	28 -1	-2

26A. HOW DO YOU THINK THE TALKING BOOK PROGRAM CAN BE IMPROVED FOR YOU (HIM/HER)?

_____ 29 -

_____ 30 -

_____ 31 -

_____ 32 -

NOTE: Ask Q.26B only of persons who used Braille materials. If Braille not used, skip to Q.26C.

26B. HOW DO YOU THINK THE BRAILLE PROGRAM CAN BE IMPROVED FOR YOU (HIM/HER)?

_____ 33 -

_____ 34 -

_____ 35 -

_____ 36 -

26C. WHAT OTHER READING SERVICES WOULD YOU (HE/SHE) LIKE?

37 -

_____ 38 -

39 -

_____ 40 -

27. THERE ARE A NUMBER OF INNOVATIONS IN THE PROGRAM SINCE YOU (HE/SHE) LAST USED IT--LIKE BETTER CASSETTE PLAYERS AND MORE CASSETTE TITLES, AND MORE MAGAZINES ON FLEXIBLE RECORDS THAT YOU (HE/SHE) CAN KEEP. DO YOU THINK THAT YOU (HE/SHE) WOULD BE VERY INTERESTED, SOMEWHAT INTERESTED, NOT VERY INTERESTED, OR NOT AT ALL INTERESTED IN TRYING THE SERVICE AGAIN?

Very interested	41	-1
Somewhat interested		-2
Not very interested		-3
Not at all interested		-4

79 -1

NOW GO TO BUFF SECTION V /END CARD 11/ 80 -1

(Continued on Page 23)

SECTION V - FOR EVERYONE

(Demographic information for everyone)

NOW I HAVE A FEW QUESTIONS ABOUT YOUR (HIS/HER) HOUSEHOLD. JUST TO REMIND YOU, ALL OF YOUR ANSWERS ARE STRICTLY CONFIDENTIAL AND ONLY FOR STATISTICAL PURPOSES.

1. ABOUT HOW LONG HAVE YOU (HAS HE/SHE) LIVED AT YOUR (HIS/HER) PRESENT ADDRESS?

11 -
_____years 12 -

13 -
_____months 14 -

NOTE: If answer to Q.1 is Less than 5 Years, ask Q.2. Otherwise, skip to Q.3.

2. HOW MANY TIMES HAVE YOU (HAS HE/SHE) CHANGED ADDRESSES IN THE PAST FIVE YEARS?

One	15 -1
Two	-2
Three	-3
Four	-4
Five or more	-5

3. DO YOU (DOES HE/SHE) LIVE IN...(read off)

A ONE- OR TWO-FAMILY HOUSE	16 -1
AN ELEVATOR APARTMENT BUILDING	-2
AN APARTMENT BUILDING WITHOUT AN ELEVATOR	-3

(Do not read) ← Other (specify)_____

4A. AT PRESENT, ARE YOU (IS HE/SHE) (read off)...

	Yes	No
TAKING CARE OF A HOME OR FAMILY	17 -1	-2
GOING TO SCHOOL OR IN TRAINING	18 -1	-2
WORKING	19 -1	-2
LOOKING FOR WORK	20 -1	-2
RETIRED FOR REASONS OF AGE OR CHOICE	21 -1	-2
NOT WORKING FOR SOME OTHER REASON	22 -1	-2

NOTE: If "Yes" to "Not working for some other reason", ask Q.4B. Otherwise, skip to note after Q.4B)

4B. ARE YOU (IS HE/SHE) NOT WORKING BECAUSE...(read off)

	Yes	No
OF POOR HEALTH OR A DISABILITY	23 -1	-2
YOU (HE/SHE) CAN'T FIND THE JOB YOU (HE/SHE) WANT(S)	24 -1	-2
YOU (HE/SHE) FEEL(S) NO JOBS ARE AVAILABLE	25 -1	-2
OR FOR SOME OTHER REASON	26 -1	-2

(If "Some Other Reason" probe: WHAT IS THAT REASON? and record below)

_____ 27 -
28 -

NOTE TO INTERVIEWER:
- If "Yes" to "working" in Q.4A, ask Q.5 through 9A, as directed.
- If "Yes" to "Going to School or in Training", ask Q. 10 through 12A as directed.
- If neither "Working" or "Going to School or in Training", skip to Q.13.

(Continued on Page 24)

SECTION V - FOR EVERYONE - Continued...

5. IN WHAT FIELD OR INDUSTRY ARE YOU (IS HE/SHE) EMPLOYED--THAT IS, WHAT DOES YOUR EMPLOYER DO OR MAKE?

_____ 29 -

_____ 30 -

6. WHAT ARE YOUR (HIS/HER) WORK DUTIES--THAT IS, WHAT DO YOU (DOES HE/SHE) DO AT YOUR (HIS/HER) JOB?

_____ 31 -

_____ 32 -

7. ABOUT HOW MANY HOURS A WEEK DO YOU (DOES HE/SHE) USUALLY WORK?

_____ hours 33 -
34 -

8. DO YOU (DOES HE/SHE) READ REGULARLY AS PART OF YOUR (HIS/HER) JOB?

Yes 35 -1
No -2

9. DO YOU (DOES HE/SHE) USE A SIGHTED READER, TALKING BOOKS, SPECIAL EYE GLASSES, PAGE TURNERS OR OTHER AIDS ON YOUR (HIS/HER) JOB?

(Ask Q.9A) ← Yes 36 -1

(Skip to note before Q.10) ← No -2

9A. WHAT AIDS DO YOU (DOES HE/SHE) USE?

37 -
_____ 38 -
39 -
_____ 40 -

NOTE: If person is also "going to school or in training" (Q.4A), continue with Q.10; otherwise, skip to Q.13.)

10. WHAT KIND OF SCHOOL OR TRAINING FACILITY ARE YOU (IS HE/SHE) NOW ATTENDING? (Probe for type of school)

41 -
_____ 42 -
43 -
_____ 44 -

11. ARE YOU (IS HE/SHE) LEARNING ANY SPECIAL READING TECHNIQUES AS PART OF YOUR (HIS/HER) COURSE OF INSTRUCTION?

(Ask Q.11A) ← Yes 45 -1

(Skip to Q.12) ← No -2

11A. WHAT ARE YOU (IS HE/SHE) LEARNING?

_____ 46 -
47 -
_____ 48 -
49 -

12. DO YOU (DOES HE/SHE) USE A SIGHTED READER, TALKING BOOKS, EYE GLASSES, PAGE TURNERS, OR OTHER AIDS AT SCHOOL OR IN TRAINING?

(Ask Q.12A) ← Yes 50 -1

(Skip to Q.13) ← No -2

12A. WHAT DO YOU (DOES HE/SHE) USE?

51 -
_____ 52 -
53 -
_____ 54 -

(Continued on Page 25)

SECTION V - FOR EVERYONE - Continued...

13. WHAT IS THE HIGHEST GRADE OF SCHOOL THAT YOU HAVE (HE/SHE HAS) COMPLETED?

55 -
_____ 56 -

NOW, I'D LIKE TO ASK YOU A FEW QUESTIONS ABOUT YOUR (HIS/HER) USE OF COMMUNITY SERVICES...

14. IN GENERAL, HOW DO YOU (DOES HE/SHE) FIND OUT ABOUT SPECIAL LEGISLATION OR LOCAL PROGRAMS FOR PERSONS WITH PHYSICAL PROBLEMS? I MEAN, FOR EXAMPLE, A NEW HEALTH SERVICE, OR REDUCED FARES ON PUBLIC TRANSPORTATION? (Probe for organizations, people, media)

_____ 57 -
58 -
_____ 59 -
60 -
_____ 61 -
62 -

79 -1
/END CARD 12/ 80 -2

15A. THINKING ABOUT THE PAST MONTH, WHICH OF THE FOLLOWING SERVICES HAVE YOU (HAS HE/SHE) USED? (Read off and record in grid below under Q.15A.)

15B. (For each service used--"Yes" in Q.15A--ask:) WHAT ORGANIZATION OR PERSON PROVIDED THIS SERVICE? (Record below under Q.15B.) (Probe for complete explanation of organization.)

	Q.15A Service Yes	No	Q.15B Organization or Person	
				20 -
VISITS FROM A HOME TEACHER OR NURSE	11 -1	-2	_____	21 -
				22 -
			_____	23 -
VOCATIONAL TRAINING	12 -1	-2	_____	24 -
				25 -
			_____	26 -
				27 -
COUNSELING	13 -1	-2	_____	28 -
				29 -
			_____	30 -
				31 -
MEDICAL CHECK-UP OR TREATMENT FROM A DOCTOR	14 -1	-2	_____	32 -
				33 -
			_____	34 -
				35 -
ORGANIZED RECREATIONAL SERVICE	15 -1	-2	_____	36 -
				37 -
			_____	38 -
				39 -
HELP IN SHOPPING OR HOUSEWORK FROM SOMEONE OUTSIDE YOUR (HIS/HER) HOME	16 -1	-2	_____	40 -
				41 -
			_____	42 -
				43 -
HELP IN TRAVELING	17 -1	-2	_____	44 -
				45 -
			_____	46 -
				47 -
DO YOU (DOES HE/SHE) USE ANY OTHER ORGANIZED SOCIAL SERVICE (specify service)				48 -
				49 -
	18 -			50 -
_____	19 -		_____	51 -
				52 -
			_____	53 -
				54 -
				55 -

(Continued on Page 26)

SECTION V - FOR EVERYONE - Continued...

15C. IN THE PAST, HAVE YOU (HAS HE/SHE) EVER HAD ANY SPECIAL TRAINING OR REHABILITATION FOR YOUR PHYSICAL OR READING PROBLEM?

(Continue with Q.15D) ← Yes 56 -1

(Skip to Q.16) ← No -2

15D. WILL YOU PLEASE EXPLAIN IT?

_____ 57 -

_____ 58 -

_____ 59 -

_____ 60 -

15E. HOW LONG DID THIS LAST? (Specify days, weeks, months or years)

61 -

_____ 62 -

63 -

64 -

16. FINALLY, WE HAVE JUST A FEW MORE QUESTIONS ABOUT YOUR (HIS/HER) HOUSEHOLD. WHAT LANGUAGE IS SPOKEN MOST OFTEN IN YOUR (HIS/HER) HOME?

English 65 -1

Other (specify)_____ 66 -

67 -

17. WHAT LANGUAGES, INCLUDING ENGLISH, CAN YOU (HE/SHE) READ?

English 68 -1

Other (specify)_____ 69 -

70 -

71 -

72 -

18. WHAT TERM BEST DESCRIBES YOUR (HIS/HER) COLOR OR BACKGROUND? (Read off)...

HISPANIC OR MEXICAN AMERICAN 73 -1

BLACK -2

WHITE -3

AMERICAN INDIAN -4

ORIENTAL -5

OTHER (specify)_____

19. Record sex of handicapped person

Male 74 -1

Female -2

_____ 79 -1

/END CARD 13/ 80 -3

20. WHAT WAS YOUR (HIS/HER) AGE AT YOUR (HIS/HER) LAST BIRTHDAY?

11 -

_____years 12 -

(Continued on Page 27)

SECTION V - FOR EVERYONE - Continued...

21. THE NEXT QUESTION HAS TO DO WITH INCOME. YOUR ANSWER IS STRICTLY CONFIDENTIAL, AS ARE ALL OF YOUR ANSWERS. AS I READ THE FOLLOWING INCOME GROUPS, PLEASE TELL ME INTO WHICH GROUP YOUR (HIS/HER) TOTAL 1976 HOUSEHOLD INCOME BEFORE TAXES FALLS. WAS IT...(read off)

LESS THAN $5,000	13 -1
$5,000 TO $9,999	-2
$10,000 TO $14,999	-3
$15,000 TO $19,999	-4
$20,000 TO $29,999	-5
$30,000 OR MORE	-6

22. FINALLY, TO WIND UP, WOULD YOU TELL ME WHAT YOU FEEL ARE THE MOST POSITIVE AND NEGATIVE ASPECTS OF YOUR (HIS/HER) LIFE NOWADAYS?

Positive:_____ 14 -
15 -
_____ 16 -
17 -
_____ 18 -
19 -
_____ 20 -
21 -
_____

Negative:_____ 22 -
23 -
_____ 24 -
25 -
_____ 26 -
27 -
_____ 28 -
29 -
_____

23. IS THERE ANYTHING THAT YOU WOULD LIKE TO ADD BEFORE WE FINISH?

_____ 30 -
_____
_____
_____

I WANT TO THANK YOU VERY MUCH FOR BEING SO HELPFUL AND SO GENEROUS WITH YOUR TIME. I HOPE THE INTERVIEW HAS BEEN ENJOYABLE FOR YOU. YOU HAVE PROVIDED US WITH INFORMATION THAT WILL RESULT IN HELPING YOU AND THOUSANDS OF OTHER PEOPLE. THANK YOU AGAIN. GOODBYE.

79 -1
/END CARD 14/ 80 -4

TIME ENDED:_____

NOTE TO INTERVIEWER: Please fill in the information on the next page immediately.

INTERVIEWER REPORT FORM

1A. WAS THE RESPONDENT...

VERY COOPERATIVE	11	-1
SOMEWHAT COOPERATIVE		-2
NOT COOPERATIVE		-3
HOSTILE		-4

1B. (If "Hostile") WHAT SEEMED TO BE THE PROBLEM?

_____ 12 -

_____ 13 -

_____ 14 -

_____ 15 -

2A. DID THE RESPONDENT SEEM TO ENJOY THE INTERVIEW...

VERY MUCH	16	-1
MODERATELY		-2
NOT AT ALL		-3

2B. (If "Not at all") WHAT SEEMED TO BE THE PROBLEM?

_____ 17 -

_____ 18 -

_____ 19 -

_____ 20 -

3. DID THE RESPONDENT SEEM TO FIND THE INTERVIEW...

VERY INTERESTING	21	-1
MODERATELY INTERESTING		-2
NOT PARTICULARLY INTERESTING		-3

4. WHAT TOPICS SEEMED TO MAKE THE RESPONDENT HAPPY? WHICH MADE HIM/HER UNEASY OR WERE DIFFICULT TO ANSWER?

	Happy	Uneasy/ Difficult to answer
MEDICAL QUESTIONS	22 -1	-2
DISABILITY/MOBILITY QUESTIONS	23 -1	-2
PERSONAL QUESTIONS ON RACE, INCOME, LANGUAGE	24 -1	-2
READING QUESTIONS	25 -1	-2
USE OF TALKING BOOK PROGRAM	26 -1	-2
ACTIVITIES	27 -1	-2
FRIENDS OR NEIGHBORS	28 -1	-2
OTHER (specify)		
_____	29 -1	-2
_____	30 -1	-2
_____	31 -1	-2
_____	32 -1	-2
NONE	33 -1	-2

(Continue on Page 29)

INTERVIEWER REPORT FORM Continued...

5. DID THE RESPONDENT SEEM TO BE...

	Yes	No
CONFIDENT	34 -1	-2
HAPPY	35 -1	-2
DEPRESSED	36 -1	-2
VERY LONELY	37 -1	-2

6. IS THERE ANYTHING ELSE WE SHOULD KNOW ABOUT THIS INTERVIEW OR ABOUT SPECIFIC ANSWERS IN IT? WERE THERE ANY ACTIONS OR OPINIONS EXPRESSED BY THE RESPONDENT WHICH SEEMED TO REFLECT HIS/HER ATTITUDE ABOUT HIMSELF/HERSELF, OR LIFE IN GENERAL?

_____ 38 -

_____ 39 -

_____ 40 -

_____ 41 -

_____ 42 -

_____ 43 -

FOR PROXY INTERVIEWS, please record the following:

1. DID HANDICAPPED PERSON PARTICIPATE IN INTERVIEW...

A GREAT DEAL	44 -1
A FAIR AMOUNT	-2
VERY LITTLE	-3
NOT AT ALL	-4

2. WAS HANDICAPPED PERSON WITHIN HEARING DISTANCE OF THE TELEPHONE?

YES	45 -1
NO	-2

3. COULD YOU HEAR HIM/HER SPEAK IN RESPONSE TO ANY QUESTIONS?

YES	46 -1
NO	-2

4. DID YOU FEEL THAT THE PROXY WAS INTERJECTING HIS/HER OWN OPINIONS?

YES	47 -1
NO	-2

THANK YOU VERY MUCH.

_____ 79 -1

/END CARD 15/ 80 -5

Appendix C

Institutional Mail Questionnaire

AMERICAN FOUNDATION FOR THE BLIND, INC.
15 WEST 16TH STREET, NEW YORK, N.Y. 10011/TEL. (212) 924-0420

January, 1978

Dear Executive Director:

- WHAT KINDS OF SERVICES WILL BEST MEET THE NEEDS OF YOUR RESIDENTS/PATIENTS WHO HAVE READING PROBLEMS?
- WHAT KINDS OF PROBLEMS DO SUCH SERVICES POSE FOR INSTITUTIONS?

The Library of Congress has contracted with the American Foundation for the Blind to develop a profile of persons with visual or other physical difficulties, who are unable to use regular print materials, and to study health care facilities where such persons may be institutionalized. Our ultimate objective is to develop recommendations for improvements in the Library of Congress Talking Book and Braille Program.

Your facility has been selected for a national survey of 4,000 health care institutions. We are asking you to provide insights from personal experience to help answer the above questions.

Regardless of whether you now use services like the Talking Book and Braille Program, please complete this survey. Then fold it, seal the booklet, and mail it back to us within a week. No envelope or postage is needed.

For each question, please choose the answer that comes closest to your current views or situation. You may comment further by making notes in the margin.

Your responses will be kept confidential and will be presented only in statistical reports.

Thank you for your cooperation.

Sincerely,

Marvin Berkowitz

Marvin Berkowitz, Ph.D., Director
Research & Technological Development Department

CONFIDENTIAL

SURVEY OF HEALTH CARE FACILITIES REGARDING USE OF THE LIBRARY OF CONGRESS TALKING BOOK AND BRAILLE PROGRAM

Please do not write here.

ID No. _____ 1-5

State/Region _____ 6-7

Site _____ 8

SP _____ 9

_____ 10

Name of Facility | Department of Person Completing Survey

Street Address | City | State | Zip | Telephone No. | Date

SECTION I—GENERAL READING SERVICES PROVIDED

1. **Please check the ways in which your facility makes reading matter available to any of your residents or patients.** ***(Check as many as apply)***

   a. We have a library or room specifically set aside for reading and selecting books.... ☐ 11

   b. We have an area in a lounge where books are available; the lounge is used for many types of activities including selecting of reading printed matter..... ☐ 12

   c. We use a portable cart to take selections of reading matter to people..... ☐ 13

   d. Most of our people bring their own materials for reading or have friends or families bring selections..... ☐ 14

   e. Other *(describe)*_____ ____ 15

2. **Does your facility currently receive library books from any public library or library for the blind and physically handicapped?**

   No ☐ 1 | 16

   Yes ☐ 2

   a. **IF YES, have any library staff from outside of your institution, assisted residents or patients in acquiring Talking Books and Braille materials?**

      No ☐ 1 | 17

      Yes ☐ 2

3. **Has the facility previously heard about the Library of Congress Talking Book and Braille Program?**

   No ☐ 1 | 18

   Yes ☐ 2

   a. **IF YES, how did you first hear about the Talking Book and Braille Program? Was it from:** ***(Check one)***

      • Residents/patients using the program..... ☐ 1 | 19

      • Conferences staff attended..... ☐ 2

      • Librarians..... ☐ 3

      • Printed Literature..... ☐ 4

      • Personal or family experiences..... ☐ 5

      • Agency for the Blind..... ☐ 6

      • Agency for the Physically Handicapped.... ☐ 7

      • Other *(specify)* _____ ____

      • Don't know..... ☐ 9

11/77

SECTION II—CHARACTERISTICS OF RESIDENTS/PATIENTS

Please do not write here

4. What are the *primary* diagnoses of people that you serve? *(Please check the appropriate percent of your residents/patients you estimate who cannot see well enough to read regular print or have difficulty holding or turning the pages of a book as a result of these diagnoses.)*

Primary Diagnoses:	Estimated Percent of Residents/ Patients with each Diagnosis				
	Less than 5%	6-25%	26-50%	More than 50%	
	1	2	3	4	
a. Stroke	☐	☐	☐	☐	20
b. Severe visual impairment; inability to read newspaper print, even with corrective lenses	☐	☐	☐	☐	21
c. Auditory/hearing impairment	☐	☐	☐	☐	22
d. Unable to be mobile without staff assistance	☐	☐	☐	☐	23
e. Mental deterioration associated with age; forgetful	☐	☐	☐	☐	24
f. Heart disease	☐	☐	☐	☐	25
g. Neurological disorder	☐	☐	☐	☐	26
h. Other severe physical impairments	☐	☐	☐	☐	27

5. Of those residents/patients who are unable to see regular print or have difficulty holding or turning pages of a book, about what percent would you estimate need assistance to operate a cassette or record player? *(Check one for each item.)*

	Less than 25%	25-75%	More than 75%	
	1	2	3	
a. Cassette player	☐	☐	☐	28
b. Record player	☐	☐	☐	29

6. Do you conduct regular examinations for your residents/patients at entry and/or annually or more often of the following abilities?

	At Entry		Annually or more often		
	No	Yes	No	Yes	
	1	2	1	2	
a. Visual acuity	☐	☐	☐	☐	30-31
b. Condition of the eyes	☐	☐	☐	☐	32-33
c. Physical limitations	☐	☐	☐	☐	34-35
d. Mental functioning	☐	☐	☐	☐	36-37

7. Please indicate the extent to which you record the following information on resident's/patient's chart or file.

	Not Recorded	Recorded for some	Recorded for all	
	1	2	3	
• Visual acuity (near/distant vision)	☐	☐	☐	38
• Visual disorders (cataracts, glaucoma, etc.)	☐	☐	☐	39
• Ability to read printed matter	☐	☐	☐	40
• Hearing ability	☐	☐	☐	41
• Speech discrimination ability	☐	☐	☐	42
• Ability to conduct activities of daily living (ADL)	☐	☐	☐	43
• Ability to hold or turn pages of a book or to sit up for more than a very short period of time	☐	☐	☐	44

8. Who is primarily responsible for assessing visual acuity and eye condition of residents/patients? *(Check one.)*

- Visual acuity and eye conditions are not typically assessed at this time ☐ 1 — 45
- Individual residents/patients are responsible for arranging assessments ☐ 2
- Staff of the institution typically arrange for vision assessment by appropriate physician ☐ 3
- Nursing staff typically assess vision ☐ 4
- Other *(describe)*_____ ____

9. Who is primarily responsible for assessing the physical condition of your residents/patients, particularly disabilities affecting their ability to conduct daily activities such as reading, holding a book, using a cassette or record player? *(Check one.)*

- Personal physician ☐ 1 — 46
- Staff physician ☐ 2
- Physical therapist ☐ 3
- Occupational therapist ☐ 4
- Nursing staff ☐ 5
- Physiatrist or other Rehabilitation specialist ☐ 6
- Other *(describe)*_____ ____

Please do not write here

10. **About how many residents/patients in your facility read braille?**

• 0	☐ 1	• 11-25	☐ 4	• More than 100	☐ 7
• 1-5	☐ 2	• 26-50	☐ 5	• Don't know or can't estimate	☐ 9
• 6-10	☐ 3	• 51-100	☐ 6		

47

11. **Given your facility's current resources and characteristics of your resident/patient population, which of the factors below are important influences on your use or nonuse of the Talking Book and Braille Program?** ***(Please check all important factors.)***

Resident/Patient Issues

a.	We have few people who cannot see to read or cannot hold a book	48
b.	We have few people with any other limitations affecting their reading	49
c.	Our residents/patients do not seem interested in the type of reading materials available	50
d.	Many residents/patients have hearing impairments which limit their use of records or cassettes	51
e.	Many residents/patients typically haven't read much in the past	52
f.	Many residents/patients are not motivated to use the program	53
g.	Our blind persons are generally not trained in or do not use braille	54
h.	Many residents/patients do not want to use equipment or materials that bring attention to their disabilities	55
i.	Many eligible persons are simply too ill	56

Staff Organization Issues

j.	We view the reading activities of our residents/patients typically outside our responsibilities	57
k.	We have problems certifying an individual's need for the program	58
l.	We don't have enough staff for equipment circulation among different users and for protection of the equipment from damage or loss	59
m.	We don't have enough staff to help select equipment	60
n.	We don't have enough staff to order materials	61
o.	We don't have enough staff to help operate the equipment	62
p.	We haven't the means for training staff on details of the program	63
q.	We don't view leisure time activities as a major institutional concern	64
r.	We are hesitant to be responsible for government property	65

Physical Facility Issues

s.	We have space problems storing equipment, cassettes, records and braille materials	66
t.	Multiple occupancy limits use of records or cassettes in bedrooms	67
u.	Space on table tops or bedside stands in residents'/patients' room is limited	68
v.	Aside from bedrooms, we don't have adequate space for privately listening to or using the equipment	69
w.	Use of the equipment is noisy and disturbing	70

Additional Comments

_____ 71

_____ 72

_____ 73

_____ 74

_____

SECTION III—CURRENT USE OF LIBRARY OF CONGRESS TALKING BOOK AND BRAILLE PROGRAM

12. **Do you currently have any residents/patients who use Library of Congress Talking Books and Braille materials?**

No	☐ 1	75
Yes	☐ 2	End Card 1 80 = 1
Don't know	☐ 9	

IF YES, PLEASE CONTINUE, OTHERWISE SKIP TO SECTION IV, QUESTION 24, PAGE 5.

a. **How do most of your residents/patients find out about the program?** ***(Check one.)***

• People know about the program before coming into this facility	☐ 1	6 = 0 7
• From our staff	☐ 2	
• From other residents/patients	☐ 3	
• Other *(describe)*_____	____	

13. **Which person or department is primarily responsible for each of the following?** ***(Check one for each item.)***

Item	INDIVIDUAL USER 01	FACILITY LIBRARIAN 02	NURSING STAFF 03	ACTIVITY STAFF 04	SOCIAL WORKERS 05	OCCUPATIONAL THERAPISTS 06	VOLUNTEERS 07	FAMILY 08	OTHER (Specify)	Please do not write here
a. Telling new residents/patients about Talking Books or Braille materials	☐	☐	☐	☐	☐	☐	☐	☐	_____	8-9
b. Selecting or helping select titles	☐	☐	☐	☐	☐	☐	☐	☐	_____	10-11
c. Ordering and returning materials	☐	☐	☐	☐	☐	☐	☐	☐	_____	12-13
d. Explaining equipment and materials	☐	☐	☐	☐	☐	☐	☐	☐	_____	14-15
e. Storing and maintaining cassettes or record players	☐	☐	☐	☐	☐	☐	☐	☐	_____	16-17
f. Operating cassette or record players	☐	☐	☐	☐	☐	☐	☐	☐	_____	18-19

14. **Of those persons using the Talking Book or Braille Program, about how many are:** ***(Give approximate number for each)***

a. Visually impaired ..... _____ 20-23

b. Physically handicapped .... _____ 24-27

15. **Of those persons using the Program, about how many use it:** ***(Give approximate number of each.)***

a. Daily or almost daily ..... _____ 28-31

b. At least once a week ..... _____ 32-35

c. Less than once a week .... _____ 36-39

16. **About how many residents/patients subscribe to the Program as individuals, getting their own machines and materials assigned specifically to them?**

Approximate number _____ 40-43

17. **Do you receive Talking Books or Braille materials as an institution for general use by a number of residents—that is, do you have a deposit collection?**

No ☐ 1 44

Yes ☐ 2

Don't know ☐ 9

IF YES, PLEASE CONTINUE, OTHERWISE SKIP TO SECTION IV, QUESTION 24, PAGE 5.

a. **About how many people share and use the institution's Talking Book record and cassette players?**

Approximate number _____ 45-48

18. **How do resident/patients get to use Talking Books?** ***(Check all that apply.)***

a. Materials are brought to individuals ..... ☐ 49

b. Individuals pick up materials from a secured central location ..... ☐ 50

c. Individuals use materials in their own rooms ..... ☐ 51

d. Individuals use materials in a staff supervised reading room, lounge, or all purpose room ..... ☐ 52

e. Individuals sign out for materials ..... ☐ 53

f. Materials are available in a central location which is not generally supervised by staff, such as a lounge ..... ☐ 54

g. Individuals can request particular selections that are then ordered ..... ☐ 55

h. The facility is usually sent a variety of items selected by the regional library and individuals choose from those available ..... ☐ 56

i. Other *(please describe.)*_____ 57

_____ 58

_____ _____ 59

19. **About how long has your facility been subscribing to the Program?**

- Less than 1 year ... ☐ 1
- 1-2 years ..... ☐ 2
- 2-3 years ..... ☐ 3
- 3-4 years ..... ☐ 4
- 4-5 years ..... ☐ 5
- More than 5 years .. ☐ 6
- Don't know ..... ☐ 9

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Please do not write here

20. About how many of each of the following items from the Library of Congress or a regional library does your facility have assigned to it? *(Give approximate number.)*

a.	Cassette players ..... _____	61-62
b.	Record players ..... _____	63-64
c.	Talking books and magazines .... _____	65-67
d.	Braille materials ..... _____	68-70
e.	Pillow phones ..... _____	71-72
f.	Remote control switches ..... _____	73-74
g.	Headphones ..... _____	75-76
h.	Large print items ..... _____	77-79

End Card 80 = 2

21. Please rate the relative advantages of Television, Radio, and Talking books to your residents/patients with reading problems in terms of the following scale. *(Please enter a 1, 2, and 3 for each item. 1 = BEST; 2 = NEXT BEST; 3 = THIRD BEST.)*

Item	Talking Books	Television	Radio	
a. Source of information	_____	_____	_____	6-8
b. Relaxation or relief from boredom	_____	_____	_____	9-11
c. Source of socialization	_____	_____	_____	12-14
d. Convenience to staff	_____	_____	_____	15-17
e. Intellectual stimulation	_____	_____	_____	18-20
f. Overall pleasure	_____	_____	_____	21-23

22. How serious do you find the following problems in using the Library of Congress Program? *(Check one for each item.)*

	Very Serious	Somewhat Serious	Not Serious	
	1	2	3	
a. Loss of cassettes, records, or record players	☐	☐	☐	24
b. Theft of cassettes, records, or record players	☐	☐	☐	25
c. Breakdown of equipment	☐	☐	☐	26
d. Slowness in equipment repair	☐	☐	☐	27
e. Slowness in receiving ordered materials	☐	☐	☐	28
f. Other problem *(describe)*_____				
_____	☐	☐	☐	29
			_____	30-31

23. How long ago did you last experience problems in the breakdown of your Talking Book equipment?

- Within the last three months ..... ☐ 1 — 32
- Within the last four to six months ..... ☐ 2
- Within the last seven to 12 months .... ☐ 3
- Within the last year to two years ..... ☐ 4
- More than two years ago ..... ☐ 5
- Don't know ..... ☐ 9

NOW, SKIP TO QUESTION 25, SECTION V, PAGE 6, AFTER COMPLETING QUESTION 23

SECTION IV—FORMER USERS OR NON-USERS OF LIBRARY OF CONGRESS PROGRAM

24. Has your facility ever used the Talking Book and Braille Program, and then stopped using it?

No, we never used it ..... ☐ 1 — 33
Yes, we used it and stopped ..... ☐ 2

a. Please explain reasons why the Program might not be appropriate for your facility's use or describe the main reasons for no longer using the Program.

_____ 34-35
_____ 36-37
_____ 38-39

b. If you stopped using the Program, about how long ago was that?

- Within the last year ..... ☐ 1 — 40
- One or two years ago ..... ☐ 2
- More than two years ago ..... ☐ 3
- Don't know ..... ☐ 9

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Please do not write here

SECTION V—BACKGROUND INFORMATION

25. **What is the approximate overall size of your institutional facilities?** _____ beds — 41-44

26. **When was your organization founded or established?** — 45

- Before 1900 . . ☐ 1
- 1900-1939 . . . . ☐ 2
- 1940-1949 . . . . ☐ 3
- 1950-1959 . . . . ☐ 4
- 1960-1969 . . . . ☐ 5
- 1970 or after . . ☐ 6
- Don't know . . ☐ 9

27. **Approximately what proportion of your residents/patients fall into each of the following payment groups?**

a. Medicaid	_____%	46-48
b. Medicare	_____%	49-51
c. Private paying	_____%	52-54
d. Private insurance/pension	_____%	55-57
e. Other *(specify)* _____	_____%	58-60

28. **Please check off all the services regularly available through your facility:**

a. Social services provided by consultants or volunteers	☐	61
b. Social services provided by in-house staff	☐	62
c. Physical therapy for Medicare residents/patients on premises	☐	63
d. Physical therapy as preventive maintenance	☐	64
e. Occupational therapy by Registered Occupational Therapist on staff	☐	65
f. Occupational therapy by Consulting Occupational Therapist	☐	66
g. Recreation or Activity program by in-house staff	☐	67
h. Recreation or Activity program by volunteers and/or consultants	☐	68
i. Home care/outreach services	☐	69
j. Outpatient or day care services	☐	70

End Card 3 80 = 3

29. **Please give the approximate number of beds at each level of care:**

Type of Licensure or Service	Number of Beds	
a. Hospital	_____	6-9
b. Skilled Nursing Facility	_____	10-13
c. Intermediate Care	_____	14-17
d. Board and Care (Home for the Aged, Shelter Care) with some continuous nursing assistance	_____	18-21
e. Board and Care (Home for the Aged, Shelter Care) with no continuous nursing assistance	_____	22-24
f. Other *(specify)* _____	_____	25-27
	____	28-29

30. **Estimate your overall occupancy based on % of beds filled during 1976:** — 30

- 100% . . . . . ☐ 1
- 95-99% . . . . . ☐ 2
- 75-94% . . . . . ☐ 3
- 50-74% . . . . . ☐ 4
- 25-49% . . . . . ☐ 5
- Less than 25% ☐ 6

31. **What proportion of your residents/patients fall into each of the following age groups?**

a. Under 16 years	_____%	31-33
b. 16-45 years	_____%	34-36
c. 46-65 years	_____%	37-39
d. 66-75 years	_____%	40-42
e. 76-85 years	_____%	43-45
f. Over 85 years	_____%	46-48

32. **In 1976, what was the average length of stay for your residents/patients?** — 49

- Less than 5 days . . . ☐ 1
- 5-10 days . . . . . ☐ 2
- 11-29 days . . . . . ☐ 3
- 30 days to 1 year . . . ☐ 4
- 1-2 years . . . . . ☐ 5
- 2-3 years . . . . . ☐ 6
- 3-4 years . . . . . ☐ 7
- 4 or more years . . . . ☐ 8

33. **In what type of area is your facility located?** — 50

- Primarily urban . . . . . ☐ 1
- Primarily suburban . . . . . ☐ 2
- Primarily rural . . . . . ☐ 3

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Please do not write here

34. **Other than Talking Book and Braille Program, do you provide any special services to residents/patients with vision or physical problems affecting their ability to use regular printed materials?**

No ☐ 1 — 51
Yes ☐ 2

IF YES, check what types of programs you have, and describe each:

a. Recreation ..... ☐ _____ 52
b. Reading service ..... ☐ _____ 53
c. Therapy ..... ☐ _____ 54
d. Evaluation and screening ..... ☐ _____ 55
e. Self-help discussion groups ..... ☐ _____ 56
f. Other *(specify)* ..... _____ 57-58

35. **Is your facility's program oriented toward one or more of the following objectives? *(Check those that describe the primary goals of your organization.)***

a. Return of individuals to their own homes ..... ☐ 59
b. Maintenance of individual self-reliance with minimal staff assistance ..... ☐ 60
c. Maintenance of present capabilities ..... ☐ 61
d. Mental rehabilitation ..... ☐ 62
e. Physical rehabilitation ..... ☐ 63
f. Education (primary or secondary) ..... ☐ 64
g. Short term acute care ..... ☐ 65

SECTION VI—COMMENTARY SECTION

It would be helpful if the staff or volunteer(s) involved with reading needs of the people you serve would make comments on these following points.

36. **Department or function of person responding, if different from first part of survey:**

_____

37. **Have you personally listened to any Talking Books?**

No ☐ 1 — 66
Yes ☐ 2

IF YES, do you feel that for most of the eligible users in your facility:

	No 1	Yes 2	Not Sure 9	
a. An adequate variety of topics is available	☐	☐	☐	67
b. Enough books and magazines are available within each different topic	☐	☐	☐	68
c. Books and magazines are current enough	☐	☐	☐	69
d. The language is simple enough	☐	☐	☐	70
e. The sound quality of cassettes and records is satisfactory	☐	☐	☐	71
f. The instructions for use of record and cassette players are clear enough to follow easily	☐	☐	☐	72

38. **What improvements might be made in the Talking Book and Braille Program?**

_____ 73-74
_____ 75-76
_____ 77-78

39. **Would you like a copy of the results of this study?**

No ☐ 1 — 79
Yes ☐ 2

a. **IF YES, to whom and where should it be sent?**

End Card 4

_____ 80 = 4
Name Department

_____
Address City State Zip Code

40. **Finally, do you have any additional comments?**

—THANK YOU FOR YOUR COOPERATION—
NO ENVELOPE OR POSTAGE IS REQUIRED,
JUST FOLD THE QUESTIONNAIRE, SEAL THE BOOKLET, AND MAIL.

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Appendix D

Institutional Site Questionnaire

Initial Calls-

"Hello, this is , from the American Foundation for the Blind in New York City. May I speak with your director or administrator?

"The American Foundation for the Blind is currently involved in a study of reading in institutions such as yours. We are visiting several facilities in your state during the weeks of . We are especially interested in speaking directly to staff and residents about the handicapped and vision impaired. We are trying to learn about the services you provide, the problems these people have in activities involving reading, and any experiences you may have had with Talking Books or braille users.

"This study is funded by the Library of Congress. The American Foundation for the Blind is a not-for-profit organization which provides programs, education and research.

"Do you currently use the Talking Book Program? (Explain, if not.) Regardless, we would be very interested in spending some time with you and your staff and some vision impaired and physically handicapped residents.

"Even though you have no totally blind people now (or no severely handicapped) we would be most interested in learning about the services you do provide. We tend to find many people across the country who have some vision problems or difficulties that inhibit reading, and we want to include information on this full range of people.

"The study is being done for several reasons: a) to provide general information on institutional services to blind and physically handicapped b) to learn about reading habits and problems c) to learn about use of Talking Books and braille. The results will be used as a basis for re-evaluating services and needs of institutionalized populations for a number of activities.

"Would it be possible for us to visit your facility?"

II. DISCUSSION GUIDE WITH ADMINISTRATION

A. General

1. Program Background (Origin, sponsorship, changes in focus)

2. Commentary on Types of People Served

a. Major diagnoses/needs of people served:

b. SES

c. Geographic Drawing Area (including distance this represents)

d. Where do residents/patients/clients find out about this program?

e. Referral and Admission Process:

f. In your judgment, what proportion of the people you serve choose to come here themselves? Would they have other options in this community?

g. In your judgment, what proportion of the res/pat/clients will leave this facility? _____ Where will they go?

h. Are the characteristics and needs of the people whom you serve comparable to the general population of people at this level of care?
___yes
___no: comment on differences

3. What unique services do you currently provide?

Service	Purpose	Description

continuation notes? ___yes ___no

Fac ID _____
Date _____
By LS

4. Do you have any special relationships with other community agencies/ institutions in terms of providing services? (Shared functions, outreach, consultation, education, health care)

Purpose	Agency	Frequency
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Additional sheets ___yes ___no

5. How does recreation fit into your overall service program? Is it considered a mainstay, an important element, an adjunct, or outside of your primary function?

6. What experience have you had with visually impaired individuals in this facility? (Numbers, types of needs presented)

7. Do you feel your program is geared toward visually impaired people?
   ____a. primary focus
   ____b. we can adequately accommodate needs presented
   ____c. we serve such people, but without special programs
   ____d. other:

8. ...Should it be? (Factors involved)

9. Do you feel your program is geared toward physically disabled people?
   ___a. primary focus
   ___b. we can adequately accommodate needs presented
   ___c. we serve such people, but without special programs
   ___d. other:

10. ...Should it be? (Factors involved)

11. In your assessment, how pertinent is the Library of Congress, Talking Book/Braille Materials program, in theory?

Fac ID _____
Date _____
By LS

12. How important would you candidly say that the Library of Congress Talking Book and Braille Program is in your facility?

Value:

____a. It has value for overall programming and service delivery
____b. It has value for the people who use it
____c. Its available, but we have no measure of its value
____d. It's not available, but we can see the value
____e. It is not available and would have limited applicability here

Fit: From what you know of it, does the program appear to fit with the general types and approaches to services you take, on the whole?

____a. The program is consistent with the way we deliver services
____b. The program requires some deviation from the way we typically deliver services (discuss: specificity, single use orientation, physical arrangements, responsibility for property) COMMENT

13. (Explain certification for TB & B Program): Based on this information, would you estimate:

Number of Blind People	_____	Number of These Who Might Qualify	_____	Actual Users:	_____
Number of Physically Handicapped People	_____	Number Who Might Not Be Able to Use Printed Matter and Books	_____	Actual Users Of This Type	_____
Number of People Who Would Fall in Both Categories (preceding)	_____	Number Who Might Qualify and Have Both Needs	_____	Actual Users Of This Type	_____

14. Can you conceive of any other uses of the program of Talking Books in your facility

____no
____yes (Describe WHAT, WHAT TYPES OF PEOPLE WOULD BENEFIT, EST. Nos/)

15. IF NOT CURRENT USER:

a. What are your feeling about the use of this program? (commitment?)

b. What problems do you forsee with the program?

c. What is the likelihood that this particular institution would ever use the program?
(1) ___improbable
(2) ___dependent on:_ 149 _____

15. IF NOT CURRENT USER:

d. What is the maximum number of potential users you could predict at any one time over the next three years?
____(1) none

____(2) one to three

____(3) _____

e. What staff would be involved in making a decision about use of this program?
___a. medical
___b. social
___c. administrative
___d. nursing
___e. recreational
___f. volunteer coordinator
___g. librarian
___h. other _____

16. IF YES, A CURRENT USER:

a. Do you expect your current user profile to change in the next three years?
___(1) yes: Estimated numbers: _____blind ___phys. disabled
of total TB & B _____visually impaired ___both
users
___(2) no

(3) What factors would you anticipate that contribute to this?

b. (Refer to survey on problems in use) Further explanation of any problems experienced in use of the Talking Book and Braille Program:

B. Management

1. What is the corporate structure of your organization?

2. What are the major departmental functions of your organization?

3. How does therapy fit into this structure?

4. How does recreation fit into this structure?

5. How does the medical community fit into this structure?

6. How do any special services related to vision screening, vision rehabilitation, vision education fit into this structure (i.e., what departments are involved with responsibility)?

7. How is the reimbursement rate in your area in terms of providing services that you want to offer?

8. Where would you wish to allocate additional funds?

9. What is the basic cost per day at each level of care?

10. Do you find it necessary to assess additional fees to cover:
___a. Rehabilitation

___b. Recreation

___c. Vision Assessments

___d. On-going vision care

B. Management (continued)

11. How have you become involved in this institution's program? (Experience)

12. From the following list of items, would you assign a priority for each issue in terms of your current assessment of this institution?

1 = Extremely Important 2 = High Priority 3 = Important
4 = Important, but Not a Priority 5 = Not a Concern for Us

___a. Locating staff
___b. Turnover
___c. Making the operating budget work
___d. Keeping up with changing regulations
___e. Implementing better medical care
___f. Providing the social components of care
___g. Community image
___h. Occupancy
___i. Developing innovative recreation programming
___j. Working with the Board of Directors (Sponsoring Agency)
___k. Dealing with the paper work
___l. Relating on a personal level to the residents/patients/clients
___m. Staff communication between shifts
___n. Providing staff education opportunities (in-service)
___o. Managing patient/resident/client behavior problems
___p. Renovation of facilities
___q. Dealing more effectively with sensory problems of the people served
___r. Locating new sources of revenue
___s. Dealing with the loneliness and isolation of people served
___t. Working with families
___u. Unionization or union relationships

13. Of this, extensive list, which are the most important of your current concerns? (Prioritize H = high M = 2nd highest V = 3rd highes

14. Does this list cover some of your major concerns? If NO, list:

D. FACILITY DESIGN

1. Was the original design and intent of this institution to serve the function now provided?
___a. Yes
___b. No (trace evolutionary changes, briefly)

2. Have you observed any ways in which the physical structure of this facility affects the activities of your staff and residents? _____ If yes, describe:

   a. Activities (formal)

   b. Activities (informal)

   c. Therapy

   d. Other

3. What areas of this structure and/or its contents would you characterize as being particularly well-designed?

4. Where would you like to see improvements made in the existing structure?

5. As far as you know, what special planning involved consideration of sensory function of the people whom you serve? (vision, hearing, tactile, smell)

6. As far as you have observed, does your facility design influence the ability of participants to take part in group activities?

7. Are you satisfied with the layout of bedrooms in terms of the functions that must occur in those spaces? (Comment)

8. Overall, how satisfied would you say you are with the present structure?

___a. very

___b. satisfied

___c. dissatisfied

9. Do you make major use of outdoor areas? _____If so, are you satisfied with these?

___a. very

___b. satisfied

___c. dissatisfied

10. Would you comment on facility lighting in terms of the activities that people are involved in? (Include reference to space and comment)

a. For leisure (unstructured)

b. For focused group activities

c. For dining/eating

c. Bedroom/related functions

11. Have you observed any ways in which the physical structure of this facility affects the program goals of your staff and residents? Examples.

12. If a designer were to consult with you before building a new facility, which had the same function as yours, what recommendations would you have?

13. Do you tender any "pet hypotheses" about the use of this facility and how it influences the independence/dependence of the residents?

14. Have you made any changes or done any experimenting with this facility in terms of design or re-organization of rooms or spaces? Please describe.

III. ACTIVITY/RECREATION SERVICES

A. Examples

1. What are some examples of recreation activities you offer?

Frequency

a. Social/Assemblage _____

b. Social/Small Group

c. Special Interest/Participatory

d. Craft

e. Educational

f. Therapeutic

g. Sensory (music listening, record listening, reading)

h. Mental Health/Therapeutic

i. Individualized Hobbies

j. Outdoor Activities

2. Do you observe much interest among the people you serve in reading?
___a. Almost everyone reads regularly
___b. About 3/4 read regularly
___c. About 1/2 read regularly
___d. About 1/4 read regularly
___e. Less than 10% read regularly
___f. Hardly anyone seems to read regularly

3. When people do read, when in their day is this likely to occur?

(a) ___(1) very early morning
___(2) mid morning
___(3) after lunch
___(4) before dinner
___(5) before bed

(b) ___(1) when there are a lot of staff on duty
___(2) when staffing levels are lower

4. Have you gotten involved with special adaptations in terms of the needs of physically or sensory impaired residents (describe):

5. Do you work with any agencies or groups in serving these people (example: services for the Blind, volunteer groups)

6. Are there volunteers or staff available to read to residents? How often do they come?

7. Do you have available access to adaptive equipment for close work? (Magnifiers, etc.)

8. Where in the facility do you activity programs occur?

Type of Program	Area
	1. Crafts Room
	2. On unit lounges
	3. Multipurpose rooms
	4. Dining Room
	5. Bedrooms
	6. Occupational Therapy
	7. Outdoors
	8. Other_____

9. Are there seasonal variations in your programs? (Comment)

10. In your recreation program, how are the following handled--as appropriate?

    a. Determining interests of patients/residents

    b. Determining abilities of patients/residents

    c. Deciding on what types of activities will be offered

    d. Deciding when activities will be offered

    e. Obtaining necessary volunteers

    f. Transporting people to activities

    g. Transporting activities to people

    h. Ordering materials and supplies

    i. Selecting materials and supplies

    j. Storing

11. Do you have much time, with your schedule, to meet individual recreation needs of people here or to work one a one-to-one basis?

12. What observations would you have on the adequacy of the following?

    a. Space for close work? Lighting...?

    b. Space for group work? Lighting...?

    c. Acoustics in terms of your programming?

    d. Storage?

13. What improvements could you suggest to increase the planning of space/ arrangement of furnishings to enhance your recreation program?

14. Are there any factors which you could suggest that would increase the likelihood that people would read?

15. Do you have any special groups or activities for visually impaired people?

16. When visually impaired people are in groups with other residents, what types, if any, of adaptations have you had to make?

17. Explain certification process for LC Talking Books and Braille Material. Have you ever had any difficulties in certifying a person for these materials?

18. Do you currently use records or tape recorders, in general, in your recreation programming? (Describe)

19. Have you had occasion to utilize the Talking Book program in group activities?

AMERICAN FOUNDATION FOR THE BLIND
Library of Congress Study/On Site Institutions

D. Pat/Res Int Orig Fin
Fac ID _____
Date _____
By LS

RESIDENT/PATIENT INTERVIEW

1. Would you tell me about some of the things you do here? (probe)

Activity	Commentary on Ease	Frequency	Place

2. How did you find out about _____; how did you happen to come here? (Circumstances, choice)

3. As the result of the things you find easy or difficult to do, are you involved in any special therapy programs?

Therapy	Frequency	Place

4. With your present activities and conditions, do you read or do close work?

a. No (comment of circumstances: interest, ability, materials, other)

b. Yes (special adaptations)

c. If it were possible, would you like to do more reading?

(1) no

(2) yes

If yes, what would that take, do you think?

Fac ID _____

Date _____

By LS

5. Some people have said that building and furniture arrangement affect our independence or the activities we participate in. Are there any areas of this facility that are difficult for you to negotiate or work in?

Area of Facility	Reason for Use	Comment on Design
a. Bedroom		
b. Hallways		
c. Activity Room		
d. Lounge		
e. Outdoor areas		
f. Dining room		
g. _____		
h. _____		

6. Overall, do you find you have trouble with your eyes?

   a. Recognizing people in the hall or at the door?

   b. Doing close work

   c. Finding your way

   d. Reading

   e. Getting tired

7. Comments on lighting:

8. Physical characteristics:

9. Ambulation

10. Vision Ability

11. Hearing

12. Other needs:

13. Response to interview(er)

14. Talking Book and Braille Material Use Comments

Fac ID _____
Date _____

VI. PROFILE OF PEOPLE SERVED

By: LS -

---

1. Do you currently have any statistical summary of vision ability of your population? (If yes, ask for copy or summary)

2. Would you estimate the mode of ambulation for your patients/residents/clients based on the following:

On Unit		Off Unit
_____	a. No prosthesis	_____
_____	b. Use hadrails, walls, other building supports	_____
_____	c. Cane	_____
_____	d. Walker	_____
_____	e. Wheelchair	_____
_____	f. Geriatric Wheelchair	_____

3. Overall, what proportion of the residents....

_____a. Are dependent on someone for assistance, regardless of prosthesis

_____b. Are basically self-reliant, regardless of prosthesis

4. About what proportion are hearing impaired?

____ a. Deaf

____ b. Major hearing loss

____ c. Some hearing loss; affecting ability to participate in conversations or enjoy records or music

____ d. No hearing loss

5. About what proportion would have great difficulties in utilizing their fingers or hands to turn the pages of a book or hold a book for any length of time?

_____

6. About what proportion would have great difficulty sustaining concentration necessary to read or to listen to records or tapes?

_____

7. About what proportion of your residents/patients/clients must be maintained on psychoactive drugs in order to control their behavior ?

High estimate _____ Low estimate_____

VII. TALKING BOOK AND BRAILLE MATERIALS

1. Please explain how your organization manages Talking Books and Braille Material.

Step	Who Initiates	Responsibility	Where	Time Involved
a. Initiating requests				
b. Making selections				
c. Ordering				
d. Filling orders				
e. Receiving orders				
f. Inventorying orders (as appropriate)				
g. Distribution				
h. Explaining materials/ machine uses				
i. Collecting materials				
j. Collecting machines				
k. Redistribution of materials				
l. Redistribution of machines				
m. Storage of machines				
n. Storage of materials				
o. Mechanical problems (identification)				
p. Mechanical problems (follow-up)				
q. Other				

2. Please comment on how your facility uses the Talking Book and Braille materials? (Is it up to individual? Do you use in group programming? Are there specific, organized plans to use? Do some staff seem more aware and interested in program than orther?)

Respondent_____

Appendix E

Telephone Questionnaire for Librarians Survey

8-5-77

time start _____
date _____ time end _____

Respondent _____

QUESTIONS FOR GUIDED INTERVIEWS OF LIBRARIANS
INSTITUTIONAL SURVEY: TALKING BOOKS AND BRAILLE PROGRAM

1. Library Name _____

2. Library Location _____

3. Primary Services of the Library

a. Check all that apply
b. Circle major services

___Book and pamphlet/periodical circulation
___Researcher's use
___Professional use
___Archives
___Community Education _____
___Learning center _____
___Mobile Facilities
___School interaction programs _____
___Services to special user groups _____
___Services to institutions
___hospitals
___housing for elderly
___housing for disabled
___adult care homes
___nursing homes
___other

4. Description of services currently provided to physically and vision impaired constituency

a. _____
b. _____
c. _____

5. Duration of time these services have been available

a. _____
b. _____
c. _____

6. Volume of service to visually and physically impaired users

a. _____
b. _____
c. _____

7. Future plans for changes in services to visually and physically impaired users:

a = Short-range (w/in 1 yr)
b = Mid-range (w/in 2-3 yrs)
c = Long range (4+ years)

_____

8. On-Site facilities for visually and physically impaired users

___no
___yes ___% of users on site ___% circulation on site

IF YES: DESCRIBE _____

SPECIFIC TO TALKING BOOKS AND BRAILLE PROGRAM OF THE LIBRARY OF CONGRESS:

9. What is the role of the library in providing Talking Books?

___ Handling the filling of mail-in request
___ Selection of topics
___ Selection of numbers of materials to be orderec
___ Direct work with clients _____
_____
_____
___ # estimate per year
___ Machine maintenance
How handled? _____
_____
_____
_____
_____
___ Other: _____
_____
_____
_____

10. Relationship between this library and others in providing Talking Books

_____
_____
_____
_____
_____

11. Sources of input to the library in serving the blind and visually/ learning impaired individuals

___ Formal panels or groups _____
_____
_____
___ Informal relationships _____
_____
_____
_____
___ Institutional relationships _____
_____
_____
_____
_____

12. What roles of institutional staff do you tend to work most closely with?

___ Nursing
___ Recreation
___ Volunteer Director
___ Administrator
___ Rehabilitation
___ Other _____
_____
_____

13. Major Problems in reiating to institutions

___ No identifiable contact person
___ Lack of interest of staff in the program
___ Staff turn-over requires constant repetition of training
___ Communication
___ Equipment breakage or loss
___ Inadequate library staff to work with institutic
___ Inadequate library staff for personal contact with institutions
___ Other _____
_____

14. Does this library have a staff member with specific responsibilities for serving institutionalized Talking Book and Braille Material users?

___no
___yes (describe function)_____
_____
_____
_____
_____ years this position has existed

15. Have any of your staff received special training in working with the blind and physically disabled?

___no
___yes (describe)

Would you think such training would be desirable?

___no
___yes

16. Have any of your staff special experience or training in working with institutions for aged or disabled?
Would you think such training would be desirable?

___no
___yes

17. Does your library provide any referral services or respond to informational questions about location of services for blind and or physically disabled persons?

___no
___yes, describe:_____
_____
_____
_____
_____
____volume of requests/year

18. Would you please share any recommendations you might have for improving the service delivery in Talking Book and Braille Programs?

_____
_____
_____
_____
_____
_____
_____

19. Would you also share any recommendations you have on the mechanical equipment related to Talking Books?

Record Players: _____
_____
_____
_____
_____
_____
_____

Tape Machines: _____
_____
_____
_____

Other: _____
_____
_____
_____

RECOMMENDATIONS REGARDING OVERALL LIBRARY SERVICES:

20. Describe your working relationship with the Library of Congress _____

21. What are your major difficulties in working with Library of Congress?

___Awaiting Orders

___Getting specific content or types of materials

___Volume requested _____

___Other _____

22. Recommendations for improvement _____

SPECIFIC INFORMATION ON YOUR LIBRARY ORGANIZATION

22. What is the administrative setting of your library?

___State facility specially designed for this use

___Shared facilities with a library system (describe)_____

___Shared facilities with other service organizations _____

___Shared facilities with other organization(s) specifically serving blind or physically disabled _____

___Other_____

23. How does your location appear to influence your services?

24. Are you a private or public library?

___private

___public

25. Are you an integral part of the state library system?

___no

___yes (relationship:)_____

25. Are your programs for blind and physically disabled part of the state's broader program of service to institutions (e.g. prisoners)?

___no

___yes (describe relationship)_____

26. What is your current budget situation?

$_____Comments: _____

27. What trends do you see in budgeting

28. What is your current staff size

_____Full-time
_____Part-time

29. What is the current population of your geographic drawing area?

What proportion of this population are you currently serving?

_____% (comments:)_____

Specificaily, what areas does that geographic drawing area include?

What are the projected trends in population and population of disabled in your area?

___increase_____
___decrease_____
___no change anticipated

30. Has your library considered any technological approaches to better serve your physically disabled or blind readers?

___no
___yes, describe_____

31. Have you any special observations on your library services to older people?

32. Do you work closely with or relate to any other state libraries serving blind and physically disabled?

___no
___yes (comment) _____

INSTITUTIONAL SURVEY RECOMMENDATIONS:

33. We are interested in learning of any institutions in your service area that might be examples for us to visit as a means of better understanding the in-use problems and successes of the Talking Book and Braille Programs.

Would you suggest any particular institutions or organizations?

Who would be the best contact person there?

TYPE OF ORGANIZATION		NAME OF FACILITY	CITY	CONTACT PERSON
1. Hospitals	A			
	B			
	C			
	D			
2. Rehabilitation Centers	A			
	B			
	C			
	D			
3. Geriatric Facilities	A			
	B			
	C			
	D			
	E			
	F			
4. Other: ____	A			
____	B			
____	C			
____	D			
____	E			

In follow-up telephone interviews, librarians were asked additional questions about organization and funding, and about use of Talking Book Topics and Braille Book Review. For example, each state's regional librarian was asked the following questions:

1. Are all your readers likely to be listed on Talking Book Topics and/or Braille Book Review subscription lists?

2. Would you estimate that you have more or fewer readers than the subscription figures (unduplicated) for TBT and BBR would indicate?

3. Can you estimate what proportion of your readers the BBR and TBT lists (unduplicated) would represent?

4. Why don't some people subscribe?

5. Would you estimate that the number of people listed in TBT and BBR would be a good index for estimating readership for your state's program? If not, why not?

6. Are there any special characteristics you have found to be associated with people who do not subscribe to TBT? (more likely to be physically handicapped, etc.) To BBR?

Appendix F

Disability Groups Questionnaire

AMERICAN FOUNDATION FOR THE BLIND, INC.

15 WEST 16TH STREET, NEW YORK, N.Y. 10011/TEL.: (212) 924-0420

QUESTIONNAIRE

Name of Persons Completing Questionnaire _____

Title _____

Organization _____

Date _____

1. Please supply estimates, data sources, and dates of the size and characteristics of your target population of:

   (We realize that the following set of problems may not all be applicable to you. Please complete the appropriate ones.)

   a). Total size of your target population _____

   Source of data _____

   Date collected _____

   Don't Know ☐

   b). Number of persons who are unable to see well enough to read regular newspaper print _____

   Source of data _____

   Date collected _____

   Don't Know ☐

   c). Number of persons who have difficulty in seeing well enough to read newspapers _____

   Source of data _____

   Date collected _____

   Don't Know ☐

d). Number of persons who are unable to hold a book or magazine _____

Source of data _____

Date collected _____

Don't Know ☐

e). Number of persons who have difficulty in holding a book or magazine _____

Source of data _____

Date collected _____

Don't Know ☐

f). Number of persons who are unable to turn the pages of a book or magazine _____

Source of data _____

Date collected _____

Don't Know ☐

g). Number of persons who have difficulty in turning the pages of a book or magazine _____

Source of data _____

Date collected _____

Don't Know ☐

h). Number of persons who have problems with concentration, attention span, following instructions, following along a line, etc. _____

Source of data _____

Date collected _____

Don't Know ☐

2. Do our estimates seem consistent with your own projections or feelings? Do they seem high or low? Do they surprise you?

_____

_____

_____

_____ _____

3. If our estimates do not seem consistent with your own projections, what factors might account for the differences?

4. What factors associated with the telephone sampling technique may account for these differences for you specific target population?

5. What factors associated with the wording of our screening questionnaire may account for differences?

6. What factors do you feel we may have overlooked in our screening procedures that we should report as limitations of our findings?

7. What suggestions would you make to improve the Library of Congess Talking Book and Braille Program (e.g. topics, service delivery, machines or equipment, etc.)?

8. Please use this space for any further comments or suggestions.

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE.

Please fold it and enclose it in the stamped, addressed envelope that we have provided, and mail it back to us as soon as possible.

AMERICAN FOUNDATION FOR THE BLIND, INC.

15 WEST 16TH STREET, NEW YORK, N.Y. 10011/TEL.: (212) 924-042

RESEARCH FINDINGS

We are reporting approximately 2.5 million persons above 5 years of age (in the non-institutional component of the population) who indicated inability or difficulty to read regular print materials due to physical and visual problems. Findings for particular problem groups are attached. Data are aggregated for impairments where too few cases were reported by themselves.

These findings are based on a national telephone screening of some 214,000 households in 1977 that asked:

1. "Are there any members of your household, including yourself, who are unable or find it difficult to read regular print even with eye glasses?"
2. "Are there any persons who are unable or find it difficult to hold or turn the pages of a book or magazine?"
3. "Are there any persons having reading difficulties because of any other physical problems?"

If the respondent gave an affirmative answer to any one of the three questions, he/she was asked several more questions concerning the persons with the reading problem:

4. "Do you, yourself have this problem?"
5. "What is your name?/What is the name of the person with this problem?"
6. "Is this person a male or female?"
7. "How old is he/she (are you)?"
8. "What is your relationship to him/her?"
9. "What is the nature of his/her/your problem?"
10. "Is this a permanent problem?"
11. "If we were to call back at a later date to discuss free Library facilities, would it be possible to talk directly with (name of person with problem) ?"
12. "Is there anyone else in your household who has difficulty reading because of a visual or physical problem?"

If yes to question 12, questions 4 - 12 were repeated.

PROJECTION OF NUMBER OF PERSONS REPORTING
INABILITY OR DIFFICULTY IN USING REGULAR PRINT MATERIALS - U.S.A. - 1977***

Nature of Problem Reported	Persons		% Reporting Permanent Problem	Age Distribution - %				Sex	
	1000's	% of Total		6-16 years	17-44 years	45-64 years	65 or older	% Male	% Female
Seeing	1500	62%	86%	5%	13%	29%	54%	36%	64%
Holding, Turning, Weakness	125	5	93	6	23	37	35	43	57
Learning	160	7	77	58	36	4	2	62	38
Undetermined (persons who did not specify the affects of their problems- like aging, stroke, heart condition, diabetes, refusals)	345	14	90	15	17	24	44	49	51
Seeing plus Holding, Turning, Weakness	40	2	97	1	8	34	57	39	61
Seeing plus Learning	20	1	81	49	30	9	12	51	49
Seeing plus Undetermined	125	5	92	5	12	24	59	36	64
Holding, Turning, Weakness plus Learning	10	*	91	44	28	20	8	64	36
Holding, Turning, Weakness plus Undetermined	40	2	94	9	12	36	44	44	56
Learning plus Undetermined	30	1	74	49	33	8	10	57	43
Seeing plus Holding, Turning, Weakness plus Learning	1	*	**	**	**	**	**	**	**
Seeing plus Holding, Turning, Weakness plus Undetermined	20	1	100	7	11	25	58	40	60
Seeing plus Learning plus Undetermined	5	*	**	**	**	**	**	**	**
Holding, Turning, Weakness plus Learning plus Undetermined	5	*	**	**	**	**	**	**	**
Seeing plus Holding, Turning, Weakness plus Learning plus Undetermined	1	*	**	**	**	**	**	**	**
TOTAL	2425	100%	87%	11%	16%	26%	47%	41%	59%

*less than 1 percent
**data insufficient to make reliable estimates
***based on calls to listed telephone numbers

Table 2 PROJECTED NUMBERS OF PERSONS WITH SELECTED CONDI RESULTING IN PRINT HANDICAPS - U.S.A. - 1977* Subject to Revision 5/7 Not for Citation

Selected Conditon	Total Persons (1000's)	Percent of Total by Nature of Problem (Percent by Type of Print Handicap)										
		Seeing	Holding, Turning, Weakness	Learning	Undetermined	Seeing + Holding, Turning, Weakness	Seeing + Learning	Seeing + Undetermined	Holding, Turning, Weakness + Learning	Holding, Turning, Weakness + Undetermined	Learning + Undetermined	Multiples of Three or More
Headache	12	20%			14%			54%		6%		6%
In the Hospital	8	25	13%		13	4%		33		4		8
Medication	10	50	3		3	17		17		7		3
Operation	73	67	9		7	2	3%	6	1%	4		2
Allergy	4	27			36	9		27				
Aging	146	33	1		46	1		14		3	1%	1
Congenital	63	48	6	4%	21	1	1	8	1	2	5	3
Brain Tumor	5	27	20	7	27			7		13		
Leukemia	1				67			33				
Unpecified Cancer	7	5			60			20		10		5
Stroke	102	14	15		37	7	1	12		9	1	3
Brain Hemorrhage	3				67			11		11	11	
Unspecified Brain Damage	35	6	2	3	43	2	1	8	2	11	18	5
Unspecified Hemorrhage	7	24			38			24		10		5
Heart Condition	65	20	2		31	1	1	26	1	9	3	9
Arteriosclerosis	25	24	1		44	1		23		6		1
Addison's Disease	3	22	11		44			11				11
Multiple Sclerosis	18	9			74	2		6		8		2
Cerebral Palsy	26	3	8		69	1		3	1	10	1	4
Parkinson's Disease	12		6		75			6	3	11		
Muscular Dystrophy	5		7		80			7			7	
Polio	4		27		36				9	27		
Epilepsy	17	6	8		37	2	2	20	1	2	16	6
Nerves	25	11	14		31	4	1	11		17	4	7
Unspec. Muscular/Motor	8		30		35	4		4	13	9		4
Diabetes	116	37		1	33	1		24		2		2
Respitory Ailments	9	16			24	8		16		28		8
Childhood Illnesses	7	55	10	5				15		10		5
Unspecified Disease	19	26	13	4	32			15		9		2
Internal Organ	14	22	2		37			15	2	12	2	7
Head Injury	8	22		9	35	9		9		4	4	9
Upper Torso injury	12	3	71			14		3		9		
Poisoning	1	67		33								
Unspecified Injury	28	38	25	3	15	3	1	6	1	5		4
Other,Unspec. Etiologies	142	31	10	2	29	6	2	7	1	6	2	5
Don't Know	79	46	2	6	37	1	2	1		1	2	2
Refused	125	6	1	1	91	1						

*based on calls to listed telephone numbers

Appendix G

Design of the Omnibus National Sample

Design of the Omnibus National Sample

The omnibus national sample used to screen households was designed by Trendex, Inc., and has been in use for over ten years for regular quarterly market and media surveys.

Trendex utilizes a multi-stage sample in which the selection rates are first set in proportion to the distributions of households in the four census regions (North East, South, North Central, West). Each of these areas is then stratified into metropolitan and non-metropolitan areas and by market size. For the metropolitan areas these are: SMSA's greater than 1 million population, SMSA's between 250,000 and 1 million persons and SMSA's between 50,000 and 250,000 persons. For the non-metropolitan areas these are: counties with small cities between 25,000 and 50,000 population and counties with less than 25,000 persons. Within each of these market areas, calls are allocated to primary sampling points (PSUs) in proportion to the number of household units.

The calls are made from about 300 areas or primary sampling units, which in the Trendex sample are counties, or toll free telephone calling areas from enumeration points within counties. The selection of the counties is based on demographic characteristics of the households (published by the Bureau of Census) and information on consumer buying behavior.

In 1977, the PSUs represented in the Trendex sample included 199 counties defined as metropolitan in character by the Bureau of the Census. These markets represented approximately 73 percent of the total U.S. households, and the sampling quotas are set in each market such that they represent approximately the same proportion of the completed interviews. The proportion of calls completed in individual PSUs is directly proportional to that county's share of the total U.S households. For example, Peoria, Illinois has about 0.63 percent of the nation's households. Consequently 0.63 percent of the completed calls in the survey were made in Peoria.

Households not within metropolitan areas are treated in the same manner. In 1977, the Trendex sample included about 125 counties outside Standard Metropolitan Statistical Areas (SMSAs). Since approximately 27 percent of the U.S. households were in these non-metropolitan areas, 27 percent of the completed calls were made in these areas.

In general, the Trendex sample is fairly representative of the nation's regional population in metropolitan and rural areas. For 1976, the Trendex sample tended to contain about six percent more married households, seven percent more households that own homes, and two percent fewer one-person households than the nation as a whole (as estimated by the U.S. Census Bureau). These might largely be a result on non-coverage of unlisted

telephone numbers. The age and occupational distribution of the head of household across the country is about the same as the U.S. population, although the survey contains two percent fewer farmers. The Trendex sample seems to be a little poorer with fewer people having incomes greater than $20,000. On the other hand, it seems to be better educated with more college graduates, which may be a quirk in the income data. It has about three percent fewer non-whites than reported by the 1976 Census estimates.

Appendix H

Nature of Problem Coding System

Coding Sheet

LEARNING

ID Number | | | | | | |

Columns: 1 2 3 4 5 6

Card 15

Item

		Card Column	Keypunch # (circle if this problem exists)
	***REJECT	7	
PERCEPTION	Dislexia/reverses, turns around words, letters, numbers/ reads, writes backwards/mirror vision	8	-1
	Trouble following a line of print/skips a line/gets mixed up along a line/eyes jump from one line to another/uses finger, guide to stay on line	9	-1
	Difficulty following instructions with several steps/takes one step at a time	10	-1
	Perception/visual perception problem/words get mixed up getting to the brain/trouble sorting information from brain/can't put words together/wrong words in wrong place/substitutes words/ trouble telling letters, words, numbers apart	11	-1
	Aphasia	12	-1
MENTAL IMPEDIMENTS	Comprehension problem/retention problem/unable to retain what was read	13	-1
	Confusion/too many directions, steps cause confusion/instructions are confusing/gets confused/inability to understand some things/ confused, mixed up, befuddled, muddled, jumbled	14	-1
	Concentration/poor, lack of, difficulty concentrating/short attention span/mind wanders	15	-1
	Hyperactive/over-active/can't sit still	16	-1
	Coordination problem/visual-motor coordination trouble/eye to hand coordination problem	17	-1
	Mental block, blockage/low, no interest/gets bored, frustrated easily/poor attitude/will not try/psychological, emotional block/personal, emotional, social problems	18	-1
	Slow learner, reader/doesn't know the hard words/has trouble with some words	19	-1
MEMORY	Memory loss, problem/forgets/can't remember	20	-1
	Senility	21	-1
	Mental retardation/Down's Syndrome/mongoloid/low I.Q./autistic/ retarded/low mentality	22	-1
	Unspecified learning problem/spelling, reading, writing problem/ can't learn to read, write, spell/behind in school	23	-1
	***REJECT	24-36	
	Headache/ migraine/head hurts/pain in head/neuralgia (affecting, affected by learning problem)	37	-1
TREATMENT	In hospital/on a machine (affecting learning problem)	38	-1
	Medication/treatment/drugs/side effects of medication, treatment (affecting learning problem)	39	-1
	Operation/surgery (affecting learning problem)	40	-1

Coding Sheet - LEARNING - Card 15 (cont'd)

	Item	Card Column	Keypunch # (Check if this problem exists)
	Allergy/allergic reaction (affecting learning problem)	41	-1
	Aging/old age/getting old (affecting learning problem)	42	-1
	Since birth/all my life/happened during childbirth/genetic/ hereditary, inherited/congenital (affecting learning problem)	43	-1
CANCER	Brain tumor/growth, cancer, malignancy in brain (affecting learning problem)	44	-1
CANCER	Leukemia/blood cancer (affecting learning problem)	45	-1
CANCER	Other/unspecified cancer/cancer in lungs, internal organs (affecting learning problem)	46	-1
HEART/BLOOD/BRAIN	Stroke/cerebrovascular disease, disorder/blood clot in brain (affecting learning problem)	47	-1
HEART/BLOOD/BRAIN	Cerebral, brain hemorrhage/bleeding in head, brain/ruptured, leaking blood vessels in head, brain (affecting learning problem)	48	-1
HEART/BLOOD/BRAIN	Other/unspecified brain damage, deterioration/disease such as meningitis (affecting learning problem)	49	-1
HEART/BLOOD/BRAIN	Other/unspecified hemorrhage, bleeding/hemorrhage, bleeding in lungs, arteries, internal organs (affecting learning problem)	50	-1
HEART/BLOOD/BRAIN	Heart trouble, condition/heart attack/high blood pressure/ hypertension/poor circulation (affecting learning problem)	51	-1
HEART/BLOOD/BRAIN	Hardening of the arteries/arteriosclerosis (affecting learning problem)	52	-1
HEART/BLOOD/BRAIN	Addison's Disease/iron deficiency in blood/blood problem (affecting learning problem)	53	-1
MUSCULAR/NERVOUS DISORDERS	Multiple Sclerosis/MS (affecting learning problem)	54	-1
MUSCULAR/NERVOUS DISORDERS	Cerebral Palsy/CP/other palsy (affecting learning problem)	55	-1
MUSCULAR/NERVOUS DISORDERS	Parkinson's Disease (affecting learning problem)	56	-1
MUSCULAR/NERVOUS DISORDERS	Muscular Dystrophy/MD (affecting learning problem)	57	-1
MUSCULAR/NERVOUS DISORDERS	Polio (affecting learning problem)	58	-1
MUSCULAR/NERVOUS DISORDERS	Epilepsy/seizures/fits/black-outs spells (affecting learning problem)	59	-1
MUSCULAR/NERVOUS DISORDERS	Nerves/nervousness/nervous condition (affecting learning problem)	60	-1
MUSCULAR/NERVOUS DISORDERS	Other/unspecified muscular , nervous diesease, disorder (affecting learning problem)	61	-1
OTHER DISEASES	Diabetes/high, low blood sugar/hypoglycemia /hyperglycemia (affecting learning problem)	62	-1
OTHER DISEASES	Respitory ailments/Tuberculosis/TB/bronchitis/emphyzema/asthma/ shortness of breath (affecting learning problem)	63	-1
OTHER DISEASES	Childhood illnesses /measles/mumps/german measles/chicken pox (affecting learning problem)	64	-1
OTHER DISEASES	Other/unspecified disease, illness (affecting learning problem)	65	-1

Coding Sheet - LEARNING - Card 15 (cont'd)

Item	Card Column	Keypunch # (Circle if this problem exists)
Problems with internal organs/kidney, thyroid, gall bladder, bladder, hormone, gland problem/colitis (affecting learning problem)	66	-1
ACCIDENT/INJURY: Injury/accident to head (affecting learning problem)	67	-1
**REJECT	68	
**REJECT	69	
Poison/alcohol, tobacco, drugs, chemical poisoning (affecting learning problem)	70	-1
Other/unspecified accident/injury (affecting learning problem)	71	-1
Other problems (affecting learning problem)	72	-1
Don't know	73	-1
N.A./Refused	74	-1

NB.: For any answers not given in this list, please see the "Index for Nature of Problem Coding'.

Coding Sheet

VISION

ID Number ☐☐☐☐☐☐

Columns: 1 2 3 4 5 6

Card 16

Item	Card Column	Keypunch # (Circle if this problem exists)
***REJECT	7	
AMOUNT OF VISION		
Legally blind	8	-1
Totally blind/no useful vision/can't see light/can't see at all	9	-1
VISION IMPEDIMENTS		
Partial vision/partially blind/can't see well/poor vision/bad eyesight/almost completely blind/low vision/can't see print, small print/can only read large print/failing, weakening eyes, vision	10	-1
Blind in one eye/can use only one eye/problem in one eye/ artificial eye	11	-1
Astinopia/eyes tire, hurt, burn, itch, water, tear, become irritated, are sensitive to light/pain, ache in eye/photophobia/can only read for certain, short length of time due to eyes tiring	12	-1
Field of vision/peripheral vision only/no central vision/tunnel vision/ central vision only/spotted vision/spots/blind spots on eye/streaks/ wall vision	13	-1
Acuity/blurriness/fogginess/black line/focusing, sharpness problem/ everything runs together/print is small, fine, close together/distorted vision/need magnifying glass to read	14	-1
NEAR/FARSIGHTED		
Nearsighted/myopia/near vision only/problem seeing far	15	-1
Farsighted/hyperopia/far vision only/problem seeing close	16	-1
Astigmatism/wavey lens/waves, bumps on lens/bifocals/both nearsighted and farsighted/nearsighted in one eye, farsighted in other	17	-1
Other/unspecified refractive problem/needs glasses, new glasses	18	-1
Cataracts/cataract operation	19	-1
Glaucoma	20	-1
RETINA		
Retrolental fibroplasia/RLF/too much oxygen, oxygen poisoning at birth	21	-1
Retinitis pigmentosis (pigmentosa)/RP	22	-1
Diabetic retinopathy	23	-1
Detached retina	24	-1
Degeneration of macula/macular problem	25	-1
Other/unspecified retinal problem, disease/deterioration of retina	26	-1
EYE - SPECIFIC PARTS		
Optic nerve problem, damage, deterioration/eye nerves/atrophy of optic nerve/underdeveloped optic nerve	27	-1
Eye muscles problem, degeneration, deterioration/motility problem/ lazy eye/weak eye muscle/cross-eyes/wall-eyes/wandering, roving eye/ no control over eye movements/strabismus/double vision/paralysis of eye	28	-1
Cornea, sclera, conjunctiva problem/disease, disorder, inflamation, ulcer, hole in cornea, sclera/conjunctivitis/scleritis	29	-1
Iris, ciliary body, choroid problem,disease, disorder/uveitis/iritis	30	-1
Auxiliary parts of eye problem/disease, disorder, inflamation, irritation of nasolacrimal gland, eyelids, tear ducts	31	-1

Coding Sheet - VISION - Card 16 (cont'd)

	Item	Card Column	Keypunch # (Circle if this problem exists)
EYE - WHOLE	Eye tumor/eye cancer/growth in eye	32	-1
EYE - WHOLE	Eye hemorrhage/ruptured, leaking blood vessels in eye/blood clot, bleeding, thrombosis in eye	33	-1
EYE - WHOLE	Eye inflamation/abcess/swelling, infection in eye	34	-1
EYE - WHOLE	Other/unspecified problem in eye/disease in eye	35	-1
	***REJECT	36	
	Headache/migraine/head hurts/pain in head/neuralgia (affecting, affected by vision)	37	-1
TREATMENT	In hospital/on a machine (affecting vision)	38	-1
TREATMENT	Medication/treatment/drugs/side effects of medication, treatment (affecting vision)	39	-1
TREATMENT	Operation/surgery (affecting vision)	40	-1
	Allergy/allergic reaction (affecting vision)	41	-1
	Aging/old age/getting old (affecting vision)	42	-1
	Since birth/all my life/birth defect/happened during childbirth/ genetic/hereditary, inherited/congenital (affecting vision)	43	-1
CANCER	Brain tumor/growth, cancer, malignancy in brain (affecting vision)	44	-1
CANCER	Leukemia/blood cancer (affecting vision)	45	-1
CANCER	Other/unspecified cancer/cancer in lungs, internal organs (affecting vision)	46	-1
HEART/BLOOD/BRAIN	Stroke/cerebrovascular disease, disorder/blood clot in brain (affecting vision)	47	-1
HEART/BLOOD/BRAIN	Cerebral, brain hemorrhage/bleeding in head, brain/ruptured, leaking blood vessels in head, brain (affecting vision)	48	-1
HEART/BLOOD/BRAIN	Other/unspecified brain damage, deterioration/disease such as meningitis (affecting vision)	49	-1
HEART/BLOOD/BRAIN	Other/unspecified hemorrhage, bleeding/hemorrhage, bleeding in lungs, arteries, internal organs (affecting vision)	50	-1
HEART/BLOOD/BRAIN	Heart trouble, condition/heart attack/high blood pressure/ hypertension/poor circulation (affecting vision)	51	-1
HEART/BLOOD/BRAIN	Hardening of the arteries/arteriosclerosis (affecting vision)	52	-1
HEART/BLOOD/BRAIN	Addison's disease/anemia/iron deficiency in blood/blood problem (affecting vision)	53	-1
MUSCULAR/NERVOUS DISORDERS	Multiple sclerosis/MS (affecting vision)	54	-1
MUSCULAR/NERVOUS DISORDERS	Cerebral palsy/CP/other palsy (affecting vision)	55	-1
MUSCULAR/NERVOUS DISORDERS	Parkinson's disease (affecting vision)	56	-1
MUSCULAR/NERVOUS DISORDERS	Muscular dystrophy/MD (affecting vision)	57	-1
MUSCULAR/NERVOUS DISORDERS	Polio (affecting vision)	58	-1
MUSCULAR/NERVOUS DISORDERS	Epilepsy/seizures/fits/black out spells (affecting vision)	59	-1
MUSCULAR/NERVOUS DISORDERS	Nerves/nervousness/nervous condition (affecting vision)	60	-1
MUSCULAR/NERVOUS DISORDERS	Other/unspecified muscular, nervous disease, disorder (affecting vision)	61	-1

Coding Sheet - VISION - Card 16 (cont'd)

	Item	Card Column	Keypunch # (Circle if this problem exists)
OTHER DISEASES	Diabetes/high, low blood sugar/hypoglycemia/hyperglycemia (affecting vision)	62	-1
	Respitory ailments/Tuberculosis/TB/bronchitis/emphyzema/asthma/ shortness of breath (affecting vision)	63	-1
	Childhood illnesses/measles/mumps/german measles/chicken pox (affecting vision)	64	-1
	Other/unspecified disease, illness (affecting vision)	65	-1
	Problem with internal organs/kidney/thyroid/gall bladder, bladder, hormone, gland problem/colitis (affecting vision)	66	-1
ACCIDENT/INJURY	Injury/accident to head (affecting vision)	67	-1
	Injury/accident to eyes (affecting vision)	68	-1
	**REJECT	69	-1
	Poison/alcohol, tobacco, drugs, chemical poisoning (affecting vision)	70	-1
	Other/unspecified accident/injury (affecting vision)	71	-1
	Other problems (affecting vision)	72	-1
	Don't know	73	-1
	N.A./Refused	74	-1

N.B.: For any answers not given in this list, please see "Index for Nature of Problem Coding".

Coding Sheet

PHYSICAL

ID Number | | | | | | |

Columns: 1 2 3 4 5 6

Card 17

Item	Card Column	Keypunch # (Check if this problem exists)
***REJECT	7	
HOLD/TURN — Problem, difficulty, unable to hold book or magazine	8	-1
HOLD/TURN — Problem, difficulty, unable to turn pages of book or magazine	9	-1
WEAKNESS — Bedridden/in a wheelchair/confined to bed/can't get around	10	-1
WEAKNESS — Weakness/problem, difficulty, unable to sit up to read/problem, difficulty, unable to read for more than a short time without becoming weak or fatigued/tires easily	11	-1
WEAKNESS — Weakness in arms, fingers, hands, limbs	12	-1
PAIN — Repeated spinal or back problems/problem, pain, cramps in back, neck	13	-1
PAIN — Pain/cramps in arms, hands, fingers, limbs	14	-1
PAIN — Other/unspecified pain/in pain/discomfort	15	-1
JOINT DISORDERS — Arthritis/stiffness/deformity/malformation in arms, hands, fingers, limbs, back, neck	16	-1
JOINT DISORDERS — Rheumatism	17	-1
JOINT DISORDERS — Gout	18	-1
Absence/amputation/missing, no arms, hands, fingers, limbs/ artifical limbs	19	-1
PARALYSIS — Paralysis/crippled arms, hands, fingers	20	-1
PARALYSIS — Paralysis/crippled upper half of body, one side of body	21	-1
PARALYSIS — Other/unspecified paralysis	22	-1
MOTOR — Involuntary motions/spasms/shaking hands, arms, fingers, body	23	-1
MOTOR — Motor problem/coordination problem/spastic	24	-1
Other/unspecified problem in arms, hands, fingers, limbs/ physically disabled, handicapped	25	-1
*** REJECT	26-36	
Headache/migraine/head hurts/pain in head/neuralgia (affecting, affected by physical problem)	37	-1
TREATMENT — In hospital/on a machine (affecting physical problem)	38	-1
TREATMENT — Medication/treatment/drugs/side effects of medication, treatment (affecting physical problem)	39	-1
TREATMENT — Operation/surgery (affecting physical problem)	40	-1
Allergy/allergic reaction (affecting physical problem)	41	-1
Aging/old age/getting old (affecting physical problem)	42	-1
Since birth/all my life/birth defect/happened during childbirth/ genetic/hereditary, inherited/congenital (affecting physical problem)	43	-1

Coding Sheet - PHYSICAL - Card 17 (cont'd)

	Item	Card Column	Keypunch # (Check if this problem exists)
CANCER	Brain tumor/growth/cancer/malignancy in brain (affecting physical problem)	44	-1
	Leukemia/blood cancer (affecting physical problem)	45	-1
	Other/unspecified cancer/cancer in lungs, internal organs (affecting physical problem)	46	-1
HEART/BLOOD/BRAIN	Stroke/cerebrovascular disease, disorder/blood clot in brain (affecting physical problem)	47	-1
	Cerebral, brain hemorrhage/bleeding in head, brain/ruptured, leaking blood vessels in head, brain (affecting physical problem)	48	-1
	Other/unspecified brain damage/deterioration/disease such as meningitis (affecting physical problem)	49	-1
	Other/unspecified hemorrhage, bleeding/hemorrhage, bleeding in lungs, arteries, internal organs (affecting physical problem)	50	-1
	Heart trouble, condition/heart attack/high blood pressure/hypertension/ poor circulation (affecting physical problem)	51	-1
	Hardening of the arteries/arteriosclerosis (affecting physical problem)	52	-1
	Addison's Disease/anemia/iron deficiency in blood/blood problem (affecting physical problem)	53	-1
MUSCULAR/NERVOUS DISORDERS	Multiple Sclerosis/MS (affecting physical problem)	54	-1
	Cerebal Palsy/CP/other palsy (affecting physical problem)	55	-1
	Parkinson's Disease (affecting physical problem)	56	-1
	Muscular Dystrophy/MD (affecting physical problem)	57	-1
	Polio (affecting physical problem)	58	-1
	Epilepsy/seizures/fits/black-out spells (affecting physical problem)	59	-1
	Nerves/nervousness/nervous condition (affecting physical problem)	60	-1
	Other/unspecified muscular, nervous disease, disorder (affecting physical problem)	61	-1
OTHER DISEASES	Diabetes/high, low blood sugar/hypoglycemia/hyperglycemia (affecting physical problem)	62	-1
	Respitory ailments/Tuberculosis/TB/bronchitis/emphyzema/asthma/ shortness of breath (affecting physical problem)	63	-1
	Childhood illnesses/measles/mumps/german measles/chicken pox (affecting physical problem)	64	-1
	Other/unspecified disease, illness (affecting physical problem)	65	-1
	Problems with internal organs/kidney, thyroid, gall bladder, bladder, hormone, gland problem/colitis (affecting physical problem)	66	-1

Coding Sheet - PHYSICAL - Card 17 (cont'd)

	Item	Card Column	Keypunch # (Check if this problem exists
ACCIDENT/INJURY	Injury/accident to head (affecting physical problem)	67	-1
	**REJECT	68	
	Injury/accident to upper torso, back, neck, spine, arms, hands, fingers (affecting physical problem)	69	-1
	Poison/alcohol, tobacco, drugs, chemical poisoning (affecting physical problem)	70	-1
	Other/unspecified accident/injury (affecting physical problem)	71	-1
	Other problems (affecting physical problem)	72	-1
	Don't know	73	-1
	N.A./Refused	74	-1

N.B.: For any answers not given in this list, please see the "Index for Nature of Problem Coding".

Coding Sheet

UNDETERMINED

ID Number [ ][ ][ ][ ][ ][ ]

Columns: 1 2 3 4 5 6

Card 18

Item	Card Column	Keypunch # (Circle if this problem exists)
***REJECT	7	
HEARING/SPEECH SOCIO-EDUCATIONAL: Never learned to read/ no, little education	8	-1
Doesn't speak, read any English	9	-1
Other/unspecified educational reason	10	-1
Personal reasons/problems with family, home, people	11	-1
Hearing problem/deafness/loss of hearing/problem with ears/partial deafness/use of one ear only/uses a hearing aid	12	-1
Speech problem, defect/difficulty sounding, pronouncing words/stutters badly / gets mixed up reading aloud / speech is slow /can't talk	13	-1
***REJECT	14-36	
Headache/migraine/head hurts/pain in head/neuralgia (affecting, affected by undetermined problem)	37	-1
TREATMENT: In hospital/on a machine (affecting undetermined problem)	38	-1
Medication/treatment/drugs/side effects of medication, treatment (affecting undetermined problem)	39	-1
Operation/surgery (affecting undetermined problem)	40	-1
Allergy/allergic reaction (affecting undetermined problem)	41	-1
Aging/old age/getting old (affecting undetermined problem)	42	-1
Since birth/all my life/birth defect/happened during childbirth/ genetic/hereditary, inherited/congenital (affecting undetermined problem)	43	-1
CANCER: Brain tumor/growth, cancer, malignancy in brain (affecting undetermined problem)	44	-1
Leukemia/blood cancer (affecting undetermined problem)	45	-1
Other/unspecified cancer/cancer in lungs, internal organs (affecting undetermined problem)	46	-1
HEART/BLOOD/BRAIN: Stroke/cerebrovascular disease, disorder/blood clot in brain (affecting undetermined problem)	47	-1
Cerebral, brain hemorrhage/bleeding in head, brain/ruptured, leaking blood vessels in head, brain (affecting undetermined problem)	48	-1
Other/unspecified brain damage, deterioration/disease such as meningitis (affecting undetermined problem)	49	-1
Other/unspecified hemorrhage, bleeding/hemorrhage, bleeding in lungs, arteries, internal organs (affecting undetermined problem)	50	-1
Heart trouble/condition/heart attack/high blood pressure/hypertension/ poor circulation (affecting undetermined problem)	51	-1
Hardening of the arteries/arteriosclerosis (affecting undetermined problem)	52	-1
Addison's Disease/anemia/iron deficiency in blood/blood problem (affecting undetermined problem)	53	-1

Coding Sheet - UNDETERMINED - Card 18 (cont'd)

	Item	Card Column	Keypunch # (Circle if this problem exists)
MUSCULAR/NERVOUS DISORDERS	Multiple Sclerosis/MS (affecting undetermined problem)	54	-1
	Cerebral Palsy/CP/other palsy (affecting undetermined problem)	55	-1
	Parkinson's Disease (affecting undetermined problem)	56	-1
	Muscular Dystrophy/MD (affecting undetermined problem)	57	-1
	Polio (affecting undetermined problem)	58	-1
	Epilepsy/seizures/fits/black-outs (affecting undetermined problem)	59	-1
	Nerves/nervousness/nervous condition (affecting undetermined problem)	60	-1
	Other/unspecified muscular, nervous disease (affecting undetermined problem)	61	-1
OTHER DISEASES	Diabetes/high, low blood sugar/hypoglycemia/hyperglycemia (affecting undetermined problem)	62	-1
	Respitory ailments/Tuberculosis/TB/bronchitis/emphyzema/asthma/ shortness of breath (affecting undetermined problem)	63	-1
	Childhood illnesses/measles/mumps/german measles/chicken pox (affecting undetermined problem)	64	-1
	Other/unspecified disease, illness (affecting undetermined problem)	65	-1
	Problems with internal organs/kidney/thyroid, gall bladder, bladder, hormone, gland problem/colitis (affecting undetermined problem)	66	-1
ACCIDENT/INJURY	Injury/accident to head (affecting undetermined problem)	67	-1
	**REJECT	68	
	**REJECT	69	
	Poison/alcohol, tobacco, drugs, chemical poisoning (affecting undetermined problem)	70	-1
	Other/unspecified accident/injury (affecting undetermined problem)	71	-1
	Other problems (affecting undetermined problem)	72	-1
	Don't know	73	-1
	N.A./Refused	74	-1

N.B.: For any answers not given in this list, please see "Index for Nature of Problem Coding".

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